# COVERAGE OF HOSPICE CARE UNDER THE MEDICARE PROGRAM

## HEARING

BEFORE THE

## SUBCOMMITTEE ON HEALTH

OF THE

## COMMITTEE ON WAYS AND MEANS
## HOUSE OF REPRESENTATIVES

NINETY-SEVENTH CONGRESS

SECOND SESSION

ON

## H.R. 5180

TO PROVIDE HOSPICE CARE UNDER THE MEDICARE PROGRAM

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# COVERAGE OF HOSPICE CARE UNDER THE MEDICARE PROGRAM

THURSDAY, MARCH 25, 1982

HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HEALTH,
*Washington, D.C.*

The subcommittee met at 9:07 a.m., pursuant to notice, in room 1100, Longworth House Office Building, Hon. Andy Jacobs, Jr. (chairman of the subcommittee) presiding.

[Press release announcing the hearing follows:]

[Press release of Friday, Feb. 26, 1982]

HON. ANDY JACOBS, JR. (D., IND.), CHAIRMAN, SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON WAYS AND MEANS, ANNOUNCES A DATE FOR A PREVIOUSLY ANNOUNCED HEARING ON H.R. 5180, A PROPOSAL TO PROVIDE COVERAGE OF HOSPICE CARE UNDER THE MEDICARE PROGRAM TO BE HELD ON MARCH 25, 1982

The Honorable Andy Jacobs, Jr. (D., Ind.), Chairman of the Subcommittee on Health of the Committee on Ways and Means, U.S. House of Representatives, today scheduled a date for the Subcommittee's previously announced hearing on H.R. 5180, to provide coverage of hospice care under the medicare program. The hearing is scheduled for Thursday, March 25, 1982, and will begin at 9:00 a.m. in room B-318 Rayburn House Office Building.

Those individuals and organizations who have filed requests to testify, by March 8, 1982, in accordance with the Chairman's press release of February 17, 1982 (Health PR #6), will be scheduled as witnesses. No additional witnesses can be accommodated on the hearing schedule if requests have not been received by the Committee by March 8, 1982. Notification will be made as soon as possible after the filing deadline by telephone, as to the scheduled appearance of each witness. If a witness finds that he cannot appear as scheduled, he may file a written statement for the record of the hearing. Witnesses are reminded to submit at least 50 copies of their testimony to the Committee office, Room 1102 Longworth House Office Building, at least 24 hours in advance of their scheduled appearance. Failure to comply with this requirement may result in the witness being denied the opportunity to testify in person.

WRITTEN STATEMENTS IN LIEU OF PERSONAL APPEARANCE

For those who wish to file a written statement for the record of the hearing, five copies are required and may be submitted through the close of business, March 31, 1982, to John J. Salmon, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. An additional supply of statements for the printed record may be furnished for distribution to the press and public if supplied to the Committee office before the hearing begins.

Chairman JACOBS. We will convene our hearings. The purpose of the hearing of the Ways and Means Health Subcommittee this morning is to hear testimony on the bill, H.R. 5180, introduced by Congressman Leon Panetta of California and co-sponsored, I am

told, by some 200 additional Members in the House of Representatives, including the very Honorable Bill Gradison, on whom the Chair calls to explain it himself.

Mr. GRADISON. Thank you, Mr. Chairman.

I am not sure I can totally rise to that challenge at this hour, but I would like to thank you for holding this hearing on H.R. 5180, which, as you indicated, has been offered in the House under the leadership of the gentleman from California, Mr. Panetta, and in the Senate under the leadership of Senator Dole of Kansas.

Hospice care for the terminally ill patient provides an alternative to the traditional inhospital care for terminally ill patients.

This bill would provide the opportunity to choose the type of care most appropriate for them.

Although hospice care is gaining growing acceptance as a substitute for traditional acute inpatient care, most hospices are not reimbursed by medicare. The inequity of the current policy prompted me to cosponsor H.R. 5180, and in so doing, encourage discussion on the merits and viability of providing medicare reimbursement for hospice care.

This hearing is particularly important because our experience with hospice care is recent and relatively limited. I believe that the testimony we hear today will guide us in developing a policy toward medicare reimbursement for hospice care.

Although I feel there are problems with the bill, I am confident they can be worked out and that we can develop a fair and equitable reimbursement policy which neither provides an expensive open-ended benefit, nor severely restricts hospice participation.

Mr. Chairman, on a personal note—I don't believe I am the only one involved in this—the Social Security Subcommittee will be meeting at 9:30 today with the objective of completing its markup on the social security disability insurance amendments.

The markup has been under way most of this week. I only mention this because some of us are forced to leave in order to make the quorum and assist in completing consideration in that legislation.

Thank you very much.

Chairman JACOBS. The Chair will state that it is my understanding that some of the witnesses have been delayed due to traffic difficulties causing lateness in arrival here.

It may prove necessary to recess the hearings for a period, both Mr. Gradison and I being members of the Social Security Subcommittee on which legislation is actually being formed this morning.

But we may have to recess at some point. Pending that, we are pleased to welcome Mr. Paul Willging, Deputy, Administrator for the Health Care Financing Administration.

Mr. Willging, both you and your scholastic excellence are welcome.

**STATEMENT OF PAUL R. WILLGING, DEPUTY ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY BARBARA COOPER, ACTING DIRECTOR, OFFICE OF DEMONSTRATIONS AND EVALUATIONS**

Mr. WILLGING. Thank you, Mr. Chairman. It is a pleasure to be able to testify today with respect to the growing hospice movement and the potential relationship of the Federal Government through its medicare program to that movement.

I am accompanied by Dr. Barbara Cooper, Acting Director of our Office of Demonstrations and Evaluations in the Health Care Financing Administration.

With your permission, Mr. Chairman, I would submit my written testimony for the record and simply summarize it in a verbal statement.

Chairman JACOBS. Without objection.

Mr. WILLGING. The hospice movement is not, in terms of at least its European antecedents, a unique phenomenon. Certainly, as far as the United States is concerned, it provides a revolutionary departure from the traditional philosophy of health care delivery in America.

That philosophy traditionally has been toward maintaining the physical well-being and health of the patient. The hospice movement suggests that that traditional philosophy must at least be augmented with somewhat of a reorientation for the needs of the patients where physical well-being and its improvement is no longer a viable option, or the needs for those patients are, indeed, to deal with the last months of their life in a comfortable, beneficial, amenable setting.

While this phenomenon is recently new in the United States, now that it has indeed caught on, its growth has been staggering. In 1979, a GAO report found approximately 59 operating hospices in the United States.

Today, we have 600 to 800 hospices in one or another form of development and operation functioning in every State of the Union.

As hospices become a more important part of the health care delivery system in the United States, we in the Health Care Financing Administration must deal with the basic issue, namely, what role should the Federal Government play with respect to the hospice movement. What, indeed, is the likelihood that hospices are an effective and efficient way to finance care for Federal beneficiaries?

I know that when one deals with the word "efficiency," Mr. Chairman, one runs the risk of looking insensitive to the clear and indisputable needs of some 300,000 medicare beneficiaries who every year die of cancer.

Yet, as we all know, health care expenditures in this country are approaching $300 billion per year annually, approximately 10 percent of the gross national product.

The Health Care Financing Administration alone will spend about $66 billion this year in terms of the health care bills of our 47 million medicare and medicaid beneficiaries.

Those budgets, as you know, have been increasing at the rate of 15 to 20 percent per year over the last few years, and constitute approximately one-fourth of all national health care expenditures.

Insensitive as we may perhaps appear, I think we have no choice but to look at the advent of a potential new benefit in terms of its impact on Federal financing and its impact on the medicare trust funds.

I think, as George Santayana first indicated, he who forgets his history is doomed to repeat it. We have a number of examples in the medicare program. Ideas which indeed were laudatory in their concept and beneficial in their proposed outcomes have brought with them financial implications that had not been foreseen when the benefits were first enacted.

I hasten to add at this point that we are not by any means suggesting that we know what the cost implications are of this proposed benefit. What I am saying is I think we should know more about the cost implications of this benefit before we see it enacted into law.

I think, frankly, we have a number of basic and as yet unanswered questions with respect to hospice care. The definition itself is not clear.

There are perhaps as many definitions of hospice care as there are operating hospices in this country. We have questions about the scope and extent of the desired services under a hospice benefit. How comprehensive should those services be? Should limits be placed on the services? Should a minimum set of services be entailed? We have yet unanswered questions in terms of the relationship of the hospice benefit to the rest of the delivery system. What should the relationship be between inpatient hospital care and a hospice benefit? What is the most effective setting for hospice care? Are there more or less effective staffing patterns?

There are questions unresolved in terms of the quality of care. Should the Federal Government establish standards for quality? Should those standards include limits designed to protect against overutilization or even underutilization?

Ultimately, from the perspective of one whose responsibility it is to worry about the integrity of the medicare trust funds, what will be the impact on those trust funds?

Can that benefit be so designed so as to be at least of comparable cost to the existing system? If not, less cost?

These are questions which we think, Mr. Chairman, should be looked at fairly intensely before we move into development of a hospice benefit for medicare.

The Health Care Financing Administration has undertaken a major activity designed to shed some light on some of these issues. In 1978, somewhat coincidentally with the expression of interest on the part of the Congress in the hospice benefit, we announced a demonstration project designed to deal with a number of these issues.

That project was actually initiated in 1980. It is due, in effect, to come to conclusion this year with data available in 1983.

It is a fairly comprehensive, fairly intensive demonstration. We have 26 hospices in the demonstration program, 14 of these are hospital based, 9 are home health agency based, three are free-

standing. The 26 hospices reflect urban and rural differences and variations in providership.

We have solicited the cooperation of medicaid State agencies. States representing 24 of the 26 sites are participating in the financing of services.

We have, coincidental with the demonstration, awarded an evaluation program grant to Brown University, funded in part by HCFA, the Robert Wood Johnson Foundation and John A. Hartford Foundation, and we have an advisory panel composed of 12 recognized health researchers who are advising the funding agencies on the evaluation.

That evaluation will include data on other groups of terminally ill patients not currently in the 26 hospices, including patients outside the demonstration but receiving hospice care and patients terminally ill receiving conventional care.

I think it is critical that we wait for the results of this demonstration, Mr. Chairman, before we begin to structure a hospice benefit.

This is not to say that we do not recognize the problems experienced today by hospices in dealing with the traditional health care delivery and financing mechanisms. We have, in effect, as a result of those mechanisms, forced hospices to compartmentalize and pigeonhole their care in terms of reimbursement systems.

We have made it difficult for hospices to be able to provide the comprehensive care that is so much a basic foundation of the hospice movement.

Yet, without sufficient information to determine the impact of hospice care, I think we would be risking adverse effects not only for our beneficiaries but for the medicare trust funds.

We do believe that the evaluation and the demonstration we have launched will shed light on some of these issues.

While we would propose that enactment of a hospice benefit be deferred until the demonstrations and evaluations are completed, we certainly, at the same time, want to offer our cooperation to this committee, to the Congress, and to the industry, so that when the demonstration is concluded, we can work together to devise the most appropriate benefit, and appropriate reimbursement mechanisms dealing with the needs of the terminally ill.

That concludes my formal statement, Mr. Chairman. I would be happy to address any questions you or your colleague may have.

[The prepared statement follows:]

STATEMENT OF PAUL R. WILLGING, PH. D., DEPUTY ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION

INTRODUCTION

I am pleased to be here today to discuss the growing hospice movement in this country and the appropriate role of the Federal Government in financing hospice care. With me today is Barbara Cooper, Director of the Office of Demonstrations and Evaluations.

The hospice concept began in 1842 when a group of Catholic widows established a hospice in Lyon, France, for poor women suffering from incurable cancer. The concept became a component of contemporary British health care in the mid-1960's and was introduced into the United States in the early 1970's with the founding of the first hospice in Connecticut.

Hospice is an important concept in the care of patients whom medical science and technology can no longer help. It provides a humanitarian way for a terminally ill patient to approach death with dignity, in relative comfort, in a supportive atmosphere, and surrounded by family members.

The emphasis in a hospice program is properly placed on care not on cure, comfort rather than rehabilitation. Active therapeutic treatment is no longer pursued nor is it deemed appropriate. Hospice involves the patient and the family as the unit of care, providing medical, social and emotional support services through bereavement. The discomforts and islolation associated with hospital stays are replaced by home-centered care in which family members are active participants.

The most important element in hospice care is concern for the individual toward whom the care is oriented. Hospice advocates for the quality of life, for living comfortably until death, for the absence of pain, for the maintenance of personal control and for the maintenance of the family.

Hospice is not a new concept of care, but is one that has not until recently been emphasized in a health care community which stresses restoration of the patient through medical technology of the highest order. However, with an enlightened approach to death and dying publised by authors such as Dr. Elisabeth Kubler-Ross, the stage was set for acceptance of hospice care in this country.

The hospice movement has grown dramatically within the last few years. In 1979, the General Accounting Office reported 59 operating hospices. Today, there is a hospice movement in every state with estimates of operating hospices ranging from 600 to 800, with several hundred others in planning stages. And where hospice care becomes more available in local communities, health insurers begin to offer a hospice benefit to their enrollees.

It is clear that the hospice concept of care is rapidly becoming a part of the Nation's health care system and we must determine what role the Federal Government should play in the hospice movement. The primary issue we are facing is not whether hospices are an appropriate way to care for the terminally ill, but whether hospices are the most effecticve and efficient way to finance that care for Federal beneficiaries.

The cost of any new form of delivering health care services is an issue of critical importance in both the public and private health care sectors. Health care expenditures in the United States are now over $250 billion annually and are approaching almost 10 percent of the GNP. This year the Health Care Financing Administration will spend about $50 billion to pay the health care bills for over 18 million medicare beneficiaries. This cost reflects a 17 percent increase from the previous year and represents about one-fifth of total national health care expenditures. Before committing the Federal Government to financing hospice care, we must determine the impact of that action on the medicare trust funds and on the particular health care needs of the beneficiaries.

## PROPOSED LEGISLATION AND CURRENT MEDICARE PROVISIONS

H.R. 5180 would provide medicare coverage of a comprehensive range of medical and social support services for terminally ill patients through hospice programs. Benefits would be expanded to include such services as outpatient and self-administered drugs, counseling services and respite care provided by an interdisciplinary team of medical professionals, social workers, and volunteers. Terminally ill medicare patients would have two opportunities to elect hospice care for a period of six months each. The medicare program would reimburse hospices for the reasonable cost of the care they provide, not to exceed a cap amount.

Many of the services covered by the bill and now provided by hospices are currently covered by medicare. These services include inpatient care in hospitals and skilled nursing facilities, physicians services, home health care services, and medical social services under the direction of a physician. H.R. 5180 would provide medicare reimbursement for these services and more delivered through a new provider, the hospice, in a different way than is currently available to medicare patients.

While we agree that a hospice can be an excellent way of coordinating health and social services for terminal patients and their families, we also recognize that there may be other ways of providing such care. Basically, we want good, comfortable care for the terminally ill, but we must be cautious about embracing benefit expansions that could lead to unexpected consequences. Our reluctance is based on our past experience. For example, in 1965 when the medicare program was enacted, I am sure that no one expected the home health benefit to grow to the point where disbursements were estimated at three-quarters of a billion dollars in fiscal year 1980 and growing at the rate of 20 percent a year. Similarly the end-stage renal disease bene-

fit, which was added by the 1972 amendments, has seen an unanticipated growth. In 1974, 18,000 patients participated in the program at a total cost to medicare of approximately $229 million. By 1981, however, expenditures had climbed to almost $1.5 billion for more than 68,000 beneficiaries. The point I am making is that this type of benefit expansion which seems harmless, frequently results in expenditures which far exceed expectations. For this reason, the administration believes we should proceed with extreme caution in this area.

### UNANSWERED QUESTIONS ABOUT HOSPICE CARE

Frankly, there are many questions about hospice care that cannot be satisfactorily answered at this time. A good example that comes to mind is the definition of hospice itself. Generally, a hospice is a health care program emphasizing management of pain and other symptoms associated with terminal illness and providing care and counseling for the family as well as the patient. In practice, however, this definition allows for a wide disparity among hospice programs in the United States. Some hospices offer only counseling services to patients while others provide a comprehensive range of medical and social services.

This is a strength of the hospice movement; its diversity and ability to meet local needs in the context of other services which are already available. However, it also presents a problem to the Federal Government because we must clearly define what we would pay for and to whom, in order to meet our responsibilities to patients, providers and the taxpayers.

Other questions that must be answered concern:

*The scope and extent of hospice services.*—How much utilization will be stimulated by the expansion of medicare services and should limits be placed on certain services? Should a broad range of supportive services be covered and if not, which ones will contribute the most toward care of the terminally ill? How comprehensive should services be and should a minimal set of services be required? What is the appropriate mix of medical and social services for the medicare population?

*The delivery system for hospice services.*—What is the relationship between inpatient hospital and inpatient hospice care? Is it best to emphasize home-centered care? To what extent should hospices be integrated with other segments of the health care community? Has any delivery setting shown itself to be more effective than others? Are certain staffing patterns more effective and efficient in providing care to the terminally ill? Are hospices a better way to care for terminally ill medicare patients than currently provided in traditional health care settings?

*The quality of hospice services.*—Will the emphasis on palliative and supportive services in hospice dilute the quality of medical care available? Should hospices be required to meet certain standards of care and if so, which ones are the critical factors in assuring quality? Are there controls that can protect against misutilization or excessive utilization of hospice services? And finally,

*The cost of hospice services.*—What will be the impact on the medicare trust funds? Considering all the variables in the concerns I have just mentioned, can a hospice benefit be designed that is of comparable or less cost than the existing system and that would provide health care of at least the same quality, in addition to other social and emotional support services?

### HCFA HOSPICE DEMONSTRATIONS AND EVALUATION

While we do not have these answers to these questions now, we have taken steps to assure that we will have them soon. The Health Care Financing Administration recognized that the hospice movement was rapidly gaining momentum and decided to examine it as a potential benefit for medicare beneficiaries. A two-year demonstration program was initiated in September 1980 to gather information on hospice care including the quality of services provided, and costs and benefits compared to the more traditional modes of health care currently available to medicare patients. New patients will not be enrolled for the purposes of the demonstration after September 1982, and the program will end in March 1983 after a 6-month phase-down period. Twenty-six hospices are participating in the HCFA program; 14 of these are hospital-based, 9 are home health agency-based and 3 are freestanding. These organizations were selected to reflect urban and rural differences as well as variations in hospice provider types. For 24 of these hospices, medicaid state agencies have also agreed to participate in the project and reimburse for services to medicaid recipients.

In conjunction with the demonstration, a national evaluation of hospice care is being conducted by Brown University. This evaluation is being supported by a grant from HCFA and funds from two private organizations: The Robert Wood Johnson

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Foundation and the John A. Hartford Foundation. The three funding agencies are being advised on the hospice evaluation by the National Hospice Advisory Panel, established at the inception of the evaluation and composed of 12 nationally recognized health researchers. Brown is studying the demonstration in terms of cost, and the use and quality of care provided to hospice patients and their families. To more clearly understand the effects of hospice care and of reimbursement for hospice care, HCFA and Brown are also gathering information on two other groups of terminally ill patients: Those served by hospices outside the demonstration and those served by hospitals and cancer centers which provide conventional medical care. A preliminary report on the hospice evaluation is scheduled to be submitted in September 1982, with the final report due the following September.

RECOMMENDATION AND CONCLUSION

It is difficult to integrate the hospice concept of care into the existing health care delivery and reimbursement system, but we must avoid the development of fragmentary services out of ignorance of overall needs. Without suficient information to determine the impact of hospices, we would be risking adverse effects to the medicare trust funds and, more importantly, to the beneficiaries by enactment of any specific legislation. We can not afford to take this risk.

We believe the HCFA demonstration and the national hospice evaluation will provide the best information available to date on hospice care for the medicare population. Consideration of a hospice benefit should be deferred at least until the demonstration and evaluation are completed. The Federal Government and private sector will then have the unique opportunity to cooperate in the design of an effective and efficient way to meet the medical, social and community needs of the terminally ill and their families.

Mr. Chairman, that concludes my prepared remarks. I would be happy to answer any questions the committee members may have.

Chairman JACOBS. Mr. Rangel.

Mr. RANGEL. Thank you, sir.

Do you have any preliminary data from the demonstrations on how much it costs per patient?

Mr. WILLGING. We have at best isolated data which we would be adverse to calling data, Mr. Rangel. The first data is not designed to come in until about September of this year.

What we have essentially is very sporadic and spotty data. I would ask Dr. Cooper to respond to that in terms of what it may look like at this point.

Ms. COOPER. We have to be especially cautious about looking at the early data, because many of the hospices had just begun and there are some start-up costs. Some of them didn't have big inpatient units and they were developing them.

So, I think, it would be a mistake just to look at the early returns which might be higher than the costs, will be once they get started.

We are seeing some things like the fact that 30 percent of the patients who elect hospices are dying within 5 days after they have chosen hospices.

Mr. RANGEL. You say that to prove the cost-effectiveness of it?

Ms. COOPER. No, that is some preliminary data that is not related to cost. I am uncomfortable, as I said, talking about the early cost data because of these high startup costs that may be reflected.

Mr. RANGEL. From the demonstrations, what services are rendered that are not covered by medicare?

Mr. WILLGING. There are a number of services not covered by medicare which are covered under the demonstrations, Mr. Rangel. For example, bereavement services. As you know, medicare does

not have an outpatient drug component, yet the palliative drugs are provided under the demonstration program.

Some of the constraints on existing benefits, for example, for the home health benefit, do not pertain to the demonstration program. For example, the requirement under the existing home health benefit is that a patient be homebound and need intermittent skilled nursing care. Those essentially have been removed for application of home health services within the context of the demonstration.

Mr. RANGEL. How many demonstrations are we sponsoring?

Mr. WILLGING. Twenty-six sites, Mr. Rangel.

Mr. RANGEL. How many in New York, do you know offhand?

Mr. WILLGING. Two in New York.

Mr. RANGEL. Do you know, Mother Cabrini, is that one?

Mr. WILLGING. Mother Cabrini is one.

Mr. RANGEL. Thank you.

Chairman JACOBS. Mr. Gradison.

Mr. GRADISON. Thank you, Mr. Chairman.

I am concerned, first of all, Dr. Willging, about when we will get the results of the study. You indicated next year.

That seems quite reasonable, but our experience with lots of HCFA studies has been that they seldom meet their deadlines.

I wonder what assurance you could give us that this will be available next year?

Mr. WILLGING. Well, I am glad you limited your concern only to HCFA studies. We have had, quite frankly in the past, difficulties in terms of deadlines, Mr. Gradison, and I would like to—but I cannot—deny that.

I have taken a fairly careful look at the schedule, both past and prospective, for the study. I think for a study of this nature, while 4 years from first gleam in the researcher's eye to the final data being available, while it sounds like a long time, I think it is, in fact, fairly expeditious, given the type of study.

We have every intention, assuming no acts of God intervene, to see the study on time and see the report written as fast as possible. I would like to promise there would be no glitches. I can only promise I am interested in this entire concept and if there is any study that I take a personal interest in, it is this one.

Mr. GRADISON. I certainly get the message loud and clear of your personal support for the concept of hospice. I don't think there is any question, but that that certainly was conveyed to me by what you said.

I think we are trying to understand what role the Federal Government should have, if any, in working out a financial arrangement through medicare, a somewhat different question.

What methods of reimbursement, if there is more than one, are you using now in these experiments?

Mr. WILLGING. My understanding, Mr. Gradison, is that it is essentially cost reimbursement subject to certain reasonableness tests. And there are limits on bereavement services; there is a limit of three such visits to the family. But it is essentially a cost reimbursement approach.

Mr. GRADISON. Dr. Willging, it is my understanding there are hospices which have organized themselves in such a manner they are getting reimbursement today.

I am concerned about the timing of this study and of our review of this whole issue for this reason, for a lot of reasons, but one is that with the enormous growth of the number of hospices and their obvious desire to obtain as much reimbursement as possible from medicare, that we may see the movement developed in a way which might not be the optimum from a point of view of controlling costs and offering of the most appropriate means of service, but may be a means of method of development that simply is the result of getting the maximum reimbursement. In our community, for example, the community-based hospice found that it could not qualify for reimbursement primarily—I am not sure I could say solely, but primarily, because it contracted out a wide range of services: dietary services, linen services, bookkeeping, a lot of other things.

The upshot was that one of our very fine community hospitals essentially is running the whole program. I don't know how much reimbursement they are getting, but they are getting reimbursement today.

I don't know to what extent this is going to happen, but it does run the risk that these programs will be broken into their pieces and the hospital-based portion would be reimbursed, which I believe it can be today, and the home-care element will be reimbursed, as it can today, but some of the other associated services, which are not eligible, will just be given perhaps less attention than they should in terms of a comprehensive program.

That is why I am worried about the timing. Would you care to comment on the extent of reimbursement today and whether this is anything to worry about?

Mr. WILLGING. I think you have put your finger on what I see as the basic dilemma we find ourselves in. The hospice movement is a movement which is, as I indicated in my testimony, a fairly dramatic departure from the normal and traditional philosophy of health care delivery, which is based on a curative as opposed to palliative and caring approach.

Given the reimbursement mechanisms we have, we have indeed, as a result of the structure of those programs, forced hospices to pigeonhole, at least in terms of reimbursement, the various services they provide; they compartmentalize them.

Can we resolve the issues that remain unresolved? We would like to move as rapidly as possible to structure an approach which is more conducive to what it is the hospice is really trying to do.

My sense is that despite the fact that that is currently a problem, the compartmentalization, that there are equally difficult potential problems in terms of simply passing the benefit with as minimal a data base as we have today.

I would like nothing better than to be able to say that we have the answers, that we can sit down and structure a bill.

In the absence of that data base, I could not even presume to discuss what a bill should look like. There are too many as yet unknowns.

We will move as expeditiously as possible. I do want to see that study completed on time. Depending on the results, I do want to be able—at least personally—to work with the industry and this committee to structure an approach dealing with the needs of the terminally ill not as truncated as what the current system forces us into.

Mr. GRADISON. Thank you, Doctor.

Thank you, Mr. Chairman.

Chairman JACOBS. Mr. Duncan.

Mr. DUNCAN. I have no questions, Mr. Chairman.

Chairman JACOBS. Mr. Rangel.

Mr. RANGEL. Doctor, I don't want to embarrass my colleague, Mr. Panetta, with these questions, so it is easy for me to ask you.

To the layman, it appears as though the very costly hospital care that a terminally ill patient has would no longer be necessary.

Now, notwithstanding the startup costs in order to set up a hospice, assuming that that was done, I can't conceive how the costs would be anywhere near one of our hospital care programs.

In other words, you need less doctors, few nurses. All you need are professionals for drugs for pain-killing and a lot of social work, that's all you need, to take care of the family and the terminally ill patient.

I know that you would rather wait until all the demonstrations are completed and so I am not asking for a definite answer today, but since some people are concerned about the additional costs to the health delivery system of the Federal impact, as a layman, I can't see where anything except a drastic reduction of costs would take place and I am not even talking about the average 5-day survival rate. This is something else.

Assuming a decision has been made by doctors and the patient and the family that medical care will no longer be given, and supportive care is now going to be given with compassion, how can there be any relationship to cost between the two?

Mr. WILLGING. Let me try to answer that, Mr. Rangel.

As a layman, and more importantly, with an interest in this hospice movement, I would have taken the same approach. To my chagrin, however, we have what we refer to as actuaries. They drive me bananas, yet they raise questions which I think are critical.

We get to a few basic issues and these are the issues we have to look at. We know, for example, that in the last 6 months of life of the terminally ill cancer patient on the medicare program, they incur, on the average, 21 days of hospital care.

If one were sure that, in effect, hospice care would substitute for all of that 21 days, one comes up with a figure in terms of the net cost, increases or decreases. But we don't know how many of those 21 days of acute care will be substituted for.

For example, a good part of that 21 days relates to inpatient care where the first diagnosis of cancer was made. Hospices will not substitute for that part of the inpatient care. We also, as we have found out in previous studies, don't necessarily save a full day of hospital care. In the way we pay hospitals under medicare, even if you free up the bed, the medicare program still pays a good part of the fixed capital costs since they are spread out across the remaining population.

We don't know, for example, what the induced utilization will be of a hospice benefit in place. Of those people diagnosed in the hospital with cancer, some 60 percent once dismissed from the hospital, never see the inside of a hospital again.

That is what our data suggests to us. How many of those 60 percent who ultimately die of cancer would, in effect, take advantage of the hospice benefit were it made available?

We don't know the degree to which reimbursement will be affected and whether we will see a growth in technology and intensity. For example, right now we don't have an outpatient drug benefit in medicare. We don't know how much that benefit would cost once it becomes available through the hospice movement. We don't know what technology will do. Some of those answers, Mr. Rangel, we will not get from our demonstration.

Hopefully, most of the basic issues can be addressed through demonstration so that we move forward in a reasonably reflective fashion.

Mr. RANGEL. Thank you. I want to join with Mr. Gradison in indicating that your concern and sensitivity to this project is certainly explained in your testimony.

Thank you.

Chairman JACOBS. That echos the sentiment of the committee and we are grateful to the administration, and to you, for your testimony. You are excused.

Mr. WILLGING. Thank you very much.

Chairman JACOBS. The subcommittee is pleased to welcome the Honorable Leon Panetta of California, the author of the bill on which this hearing is being held.

We recognize your scholarship, too, sir. You may proceed in your own manner.

## STATEMENT OF HON. LEON E. PANETTA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. PANETTA. Thank you.

Mr. Chairman, I would ask that my comments be included in the record at this point. I will try to summarize some of them. I am pleased, of course, to be before you and very thankful that you are proceeding with the hearing on H.R. 5180 to try to gather additional information concerning the issues related to hospice care.

It is my view that this proposal makes good sense medically, physically, and humanely.

Terminal illness is a trauma most families have to face at one time or another and the diagnosis of terminal illness, obviously, places tremendous psychological and financial burdens on the patient, as well as on his or her family.

Any family that has experienced terminal illness is aware of the unique problems and needs of the family and the patient during this difficult period and only recently has our society begun to recognize this issue and try to search for adequate responses.

In the last decade, for over the last 10 to 12 years, a grass-roots movement has sprung up around the Nation to provide hospice service for terminally ill patients.

We now have, as mentioned, almost 800 hospices in this country.

The point of these services is to relieve the burden of terminal illness through compassionate medical care in a setting that is sensitive to the special needs of both the patient and the family.

It is characterized by palliative, psychological, and spiritual support, which is provided to the terminally ill patient.

Care delivered by hospice recognizes, the impending death and seeks to design a program of care in accepting that situation.

Two years ago, the hospice movement came to my attention, not only by people involved in the effort, but also by patients desperately in need of hospice services.

Unfortunately, as you know, the services in large measure are not covered by the medicare program, although some hospice programs receive reimbursement under an existing provider category.

Undoubtedly, this situation, I think, represents a major gap in the medicare program. The denial of assistance here effectively denies the unique problems of the terminally ill and the proven ability of the hospice setting to address those needs.

Legislation that I have introduced tries to respond to the present inequity that exists in the medicare program. Over the last year, I have had the opportunity to work with a number of individuals and groups in the hospice movement, and persons knowledgeable in the complexities of the medicare system to try to develop this legislation.

I by no means am an expert in this area, but I have had the opportunity to work with many of these individuals and many of them will be testifying before you today on the specifics of H.R. 5180.

The point is to try to establish a separate provider category for this service. One which would include hospice care as a covered medicare benefit.

The bill recognizes the unique type of care provided by hospices and seeks to maintain the traditional characteristics of hospice programs. It provides that medicare-eligible persons who have a terminal prognosis of less than 6 months to live will be eligible for the hospice benefit and will be able to obtain comprehensive hospice services, including home care, respite care, short-term inpatient care, counseling, drugs and medications on both an inpatient and outpatient basis, as well as family bereavement care.

The legislation continues the use and active participation of volunteers in the delivery of care. In the past, I think one of the major concerns that people in the hospice movement have and one that I share, is that the intervention of the Federal Government into a given area always has the tendency to alter the makeup of that given program.

In working with people in the hospice movement, the main target here is to try to develop legislation that maintains the unique characteristics of hospice care. With this legislation, the Federal Government will not come in and provide total support to hospice programs, rather, the support of the local community, private sector and other resources which have been brought in the hospices will exist, as they do today.

Under this legislation, home care is recognized as the primary means of delivery of hospice services. However, those patients in

need of inpatient treatment will not be denied the necessary treatment to address the various medical conditions which may develop.

The hospice benefit in this bill is for patients with less than 6 months to live and, the bill provides that the patient who lives beyond 6 months and still under the care of a hospice is able to be recertificated by the hospice medical director for another 180-day period, or a total of 360 days of care.

Finally, this legislation establishes a reimbursement formula that calculates a national average to be adjusted regionally and takes into account the annual inflation rate.

But to insure that the costs of hospice reimbursement are contained, the reimbursement would be limited to 75 percent of the medicare costs for caring for a terminally ill cancer victim in the last 6 months of life.

Based on the data used in development of this legislation, it is anticipated that no hospice currently operating has costs which would exceed the limit set out in the reimbursement formula in this legislation.

Mr. Chairman, members of the subcommittee, besides the compassion and the appropriateness of hospice care, I think it is very important to look at the cost-effective form of care that is involved here.

We are talking about the need for cost effectiveness in the health care area, but it seems to me that every time people look at the costs aspect of medicare benefits or health benefits currently provided, instead of looking at alternative forms of care, there is always attention paid to cutting back on the benefits currently provided.

That is the means of trying to deal with cost escalation instead of looking at alternative forms of care that may be much more cost-effective and, frankly, may be much more beneficial to the patients involved.

If we had studies provided behind every benefit cut that has been recommended here in terms of medicare or medicaid, I would wager to say you have another 5 to 10 years of studies that would be needed.

We have existing before us what I think is a very cost-effective form of care in hospice. We are aware of the Federal budget mandates and I, as chairman of the reconciliation task force, have been particularly concerned about this effort.

It is not easy to reduce Federal expenditures in this area while trying to maintain appropriate levels of service. But the experience of the existing hospice program suggests that significant savings, significant savings, would result from encouraging the availbility of hospice care.

That is not a statement that I am just making, it is something based on studies that have, in fact, been made with regard to hospice care. Warner-Lambert Foundation, which will provide testimony later today, commissioned an independent cost analysis of the fiscal impact of caring for the terminally ill in the current medicare system, as opposed to a medicare system which included the hospice alternative.

This study concluded that this bill, if passed, would save the Medicare Trust Fund at least $15 million in the first year after enactment and as much as $130 million in the fifth year.

A number of other studies have compared the costs of hospice care and traditional care of the terminally ill and have reported savings associated with the substitution of hospice care for more acute care.

The National Cancer Institute has conducted a 3-year demonstration program on the costs of hospice care for the terminally ill. They have concluded that the most expensive hospice study reported a total cost of less than $4,500 per patient family.

On the other hand, the Warner-Lambert study, using Health Care Financing Administration data, indicated that it now costs $7,000 in medicare funds to provide health care services for the average terminally ill cancer victim.

Given the projected estimate that there are about 200,000 medicare-eligible Americans dying of cancer in this country in 1981, there is an existing cost to the Federal Government of nearly $1½ billion for terminal care in the absence of the hospice alternative as a covered service.

More typically, an average day of hospice care has been found to cost one-fifth of the average day of care for the terminally ill in the typical American hospital, according to the Warner-Lambert study.

Congressional Budget Office, which is also conducting a cost analysis of this legislation, at least on a preliminary basis, I think, is coming out with very much the same conclusions.

As we review this legislation, let us realize that there are very difficult and complex issues which must be addressed in providing medicare coverage for hospices.

At present, hospice care may be provided through home-care units or hospice units in hospitals or freestanding hospice units. This situation makes it difficult to develop comprehensive legislation to insure equal benefits will be provided to all forms of hospice care.

H.R. 5180, as developed, recognizes the divergence that exists in the hospice movement. Nevertheless, there will be comments received today which I think will be beneficial in improving the soundness of this legislation.

This legislation has broad bipartisan support. We have almost 200 coponsors of this in the House, at the present time there are close to 30 Senators who have cosponsored the Dole legislation on the Senate side.

I think there is a tremendous responsiveness that has developed in the hospice movement, not only in the country, but is being reflected in the support for this legislation.

Whether or not we all agree on every provision here, I think it is very important that we support the objective of making hospice care an available option under the medicare system.

The Federal Government must take effective actions to begin to focus more attention on the needs of the terminally ill.

While terminal illness is a reality that must be accepted, let's begin to provide these individuals with a choice as to the type of treatment they may receive.

Providing the highest quality of living for the terminally ill in their last days of life is a goal we all must strive for. In making hospice care a visible and viable alternative, this is a path we must follow and the Federal Government should support that choice, for that decisionmaking by the individual, should be provided.

I might just say in brief response to the administration's position, Mr. Chairman, that you know it has always been my experience that you can study anything you want to death. The problem in this area is that we, in fact, have 10 to 12 years of experience in the hospice movment.

There are 800 hospices out there that are currently providing hospice care. Those are demonstration projects in and of themselves in terms of the care that is being provided and the experience that they are providing.

The question it seems to me that the subcommittee has to ask is, is hospice care necessary, is it viable, is it important, does it meet a need in our country?

If the answer to that is yes, and I think the answer, even by the administration spokesman, is yes, then the next question is, does the additional information needed go to the substance of the hospice movement or does it go to the regulations and guidelines, the procedures that need to be established in support of hospice care?

I would wager to say that if, in fact, we are not dealing with the substance of hospice care and whether it is a need or not, but the other issue, very frankly, based on the experience out there today, plus, I think, the experience that could be provided by the administration in their demonstration projects on a short-order basis, I think this legislation can still move rapidly and by the time it is put into effect with regulations and guidelines, it can make use of the information from the demonstration projects.

My concern is that once it's taken 2 or 3 years to do the demonstration, you take another year to do the report, then there are positions taken and additional studies because I don't think, frankly, OMB will ever be very responsive on this legislation.

They will always be mandating additional studies in this area. I think it is incumbent upon the Congress to take the ball and run with it, because it is extremely important to try to provide care in this area.

I thank the gentleman.

[The prepared statement follows:]

STATEMENT OF HON. LEON E. PANETTA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Chairman Jacobs, members of the subcommittee, I am very pleased to have this opportunity to come before you this morning on this historic occasion to discuss legislation I have introduced to provide medicare coverage for hospice care. Moreover, I am pleased that you have convened today's hearing to receive comments on H.R. 5180 as well as gather information concerning issues related to hospice care and the effects of providing medicare coverage. It is my view that this proposal makes good sense—medically, fiscally, and humanely.

Mr. Chairman, terminal illness is a trauma that most families have faced at one time or another. A diagnosis of terminal illness places tremendous psychological and financial burdens on the patient, as well as on his or her loved ones. While any family that has experienced terminal illness is aware of the unique problems and needs of the family and patient during that difficult period, only recently has our

society begun to recognize this issue and to search for an adequate and appropriate response.

In the last decade, a grass-roots movement has sprung up around the nation to provide hospice service for terminally ill patients and their families. The point of these services is to relieve the burden of terminal illness through compassionate medical care in setting that is sensitive to the special needs of both patient and family. Hospice care is characterized by the palliative, psychological, and spiritual support which is provided to the terminally ill patient and his or her family. The care delivered by the hospice recognizes the impending death and seeks to design a program of care to better aid the patient and the family in accepting the reality of that dreadful situation.

About two years ago, the hospice movement was brought to my attention not only by people involved in the effort but also by terminally ill patients desperately in need of hospice services. Unfortunately, while hospice services are at least as important to these patients as traditional medical treatment, the Medicare program generally does not reimburse them for hospice-related costs, although some hospice programs may receive reimbursement under an existing provider category. Undoubtedly, this situation represents a major gap in the Medicare program. The denial of assistance for hospice services effectively denies both the unique problems of the terminally ill and the proven ability of a hospice setting to address those needs.

Mr. Chairman, the legislation which I have introduced is intended to respond to the present inequity that exists in the Medicare program. Over the past year, I have been working with groups in the hospice movement and persons knowledgeable in the complexities of the Medicare system to develop this legislation. H.R. 5180 would establish a separate provider category for hospice and would include hospice care as a covered Medicare benefit.

The bill recognizes the unique type of care provided by hospices and seeks to maintain the traditional characteristics of hospice programs. It provides that Medicare-eligible persons who have a terminal prognosis of less than six months to live will be eligible for the hospice benefit and will be able to obtain comprehensive hospice services, including home care, respite care, short-term inpatient care, counseling, drugs and medications on both an inpatient basis and outpatient basis, as well as family bereavement care.

This legislation seeks to continue the use and the active participation of volunteers in the delivery of care. In the past, one of the major concerns over the intervention of federal involvement into a given area has been a tendency for federal involvement to alter the make-up of a given program. In the development of this legislation, maintaining the unique characteristics of hospice has been foremost in my efforts. With this legislation, the federal government will not come in and provide total support to hospice programs; rather, the support of the local community, private, and other resources which have brought hospices where they are today, will continue to be vital for the development of the hospice movement.

Under this legislation, home care is recognized as the primary means of the delivery of hospice services. However, those patients in need of inpatient treatment will not be denied the necessary treatment to address the various medical conditions which may develop. While the hospice benefit in this bill is for patients with six months or less to live, the bill provides that a patient who lives beyond the six months and is still under the care of a hospice is able to be re-certified by the hospice medical director for another 180-day period or a total of 360 days of care. Finally, this legislation establishes a reimbursement formula which calculates a national average to be adjusted regionally and will take into account the annual inflation rate. To ensure that costs for hospice reimbursement are contained, the reimbursement for hospice care would be limited to 75 percent of the Medicare cost for caring for a terminally ill cancer victim in the last six months of life. Based on the data used in the development of this legislation, it is anticipated that no hospice currently operating has costs which would exceed the limit set out in the reimbursement formula in this legislation.

Mr. Chairman, besides the compassion and the appropriateness of hospice care, it is also recognized as a cost-effective form of care. We all are keenly aware of the federal budget cuts. No other area of the budget is in greater need of basic reform to provide cost savings than the area of health care. The cost of federal health programs has far exceeded expectations. One of the most obvious reasons for the rising federal health costs is the increasing use of expensive, new medical technology, and the growing number of elderly citizens requiring medical services. As a member of the Budget Committee, and as Chairman of the Reconciliation Task Force, I realize the difficulty of enacting any changes in health care programs to reduce federal expenditures, while at the same time working to maintain an appropriate level of

service. However, the experience of existing hospice programs suggests that significant savings would result from encouraging the availability of hospice care.

The Warner-Lambert Foundation which will provide testimony later today, commissioned an independent cost analysis of the fiscal impact of caring for the terminally ill in the current medicare system as opposed to a medicare system which included the hospice alternative. This study concluded that this bill, if passed, would save the medicare trust fund at least $15 million in the first year after enactment and as much as $130 million in the fifth year. A number of other studies have compared the costs of hospice care and traditional care of the terminally ill and have reported savings associated with the substitution of hospice care for more acute care. The National Cancer Institute conducted a 3-year demonstration program on the costs of hospice care for the terminally ill and concluded that the most expensive hospice studied reported total cost of less than $4,500 per patient/family. On the other hand, the Warner-Lambert study, using Health Care Financing Administration data indicated that it now cost more than $7,000 in medicare funds to provide health care services for the average terminally ill cancer victim, just in the last six months of life. Given the projected estimate that there were 200,000 Medicare-eligible Americans dying of cancer in this country in 1981, there was an existing cost to the Federal government of nearly a billion and a half dollars for terminal care in the absence of the hospice alternative as a covered service. More typically, an average day of hospice care has been found to cost one-fifth of the average day of care for the terminally ill in the typical American hospital, according to Warner-Lambert. The Congressional Budget Office has been requested to perform a cost analysis of this legislation, and I am awaiting the results of this study.

As we review this legislation, let us all realize the difficult and complex issues which must be addressed in providing Medicare coverage for hospices. At present, hospice care may be provided through either home care services, hospice units in hospitals, or completely free-standing hospice units. This situation makes it difficult to develop comprehensive legislation to ensure equal benefits will be provided to each form of hospice program. However, H.R. 5180, as developed, recognizes the divergence which exists in the hospice movement. Nevertheless, comments received today will be beneficial in improving the soundness of this legislation. This legislation has received bipartisan support from over 190 members of the House of Representatives, and identical legislation in the Senate introduced by Senator Dole has received the support of some 28 senators. The growth and development of the hospice movement over the past decade and the enormous support this legislation has received should clearly encourage Congress to recognize hospice care as an appropriate form of care and to go forward with including it in the federal health care financing system.

Whether or not we all agree on every provision in this legislation, I think we all do support the objective of making hospice care an available option under the Medicare system. The federal government must take effective actions and begin to focus more attention on the needs of the terminally ill. While terminal illness is a reality which must be accepted, let us begin to provide these individuals with a choice as to the type of treatment they may receive. Providing the highest quality of living for the terminally ill in their last days of life is a goal we all must strive for. Making hospice care a visible and viable alternative is a path we must follow, and federal support in this area should be provided.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to testify before you today. I look forward to working with you in the future as we seek to make this legislation a reality. Thank you.

Chairman JACOBS. Mr. Rangel.

Mr. RANGEL. Very unusual testimony from a member of the Budget Committee, but welcome.

Mr. PANETTA. I am learning from you.

Mr. RANGEL. Did you spell out in your bill, how this option is reached? Who makes the option? What protection the patient has before the option is made?

Did you work that out?

Mr. PANETTA. Is that contained in the bill, is that your question?

Mr. RANGEL. How is the decision made by the beneficiary? Does the bill specify how a decision is made for a beneficiary to elect hospice?

Mr. PANETTA. It would be done, obviously, in conjunction with a medical doctor, the patient's doctor, in a determination of whether or not the patient is terminally ill and is expected to die within a 6-month period. That would be a medical determination and it would be up to the patient to decide.

Mr. RANGEL. It is up to the individual then?

Mr. PANETTA. That's correct.

Mr. RANGEL. Do we find this concept weaving itself into medical insurance programs?

Mr. PANETTA. That's correct, more and more are beginning to provide that coverage today.

Mr. RANGEL. The data you talk about that is available under the hospitals that have decided to go into hospice programs, do you know who has that information if the administration doesn't? The questions they raise are what services are concurrent?

His response did indicate that it is difficult to decide which is a substitute service, which costs more, how much you would have to give in the hospital and then supplement that with hospices, additional treatment.

So when it comes to the cost, he did confuse it. But you did say that there are about 800 hospitals that could give us some direction as to cost, right?

Mr. PANETTA. That's correct. I think the Warner-Lambert study, which I mentioned in my testimony, which goes to the cost-effectiveness issue, they will be testifying today, but I think they can give you more backup. Every indication, as the gentleman understands better than I, the costs of a terminally ill patient in a hospital setting now are growing at tremendous sums.

To remove that patient at that patient's choice into a hospice situation, I think, clearly involves less costs.

Mr. RANGEL. Seems that way.

Mr. PANETTA. All the studies we have seen substantiate that.

Mr. RANGEL. You have a built-in cap in your bill?

Mr. PANETTA. That's correct.

Mr. RANGEL. What happens after the patient reaches the cap?

Mr. PANETTA. Our feeling was that it was important if we are going to have a shot at legislation like this, to, in fact, put a cap at 75 percent of services here.

The indication we get from the hospices currently operating is that, in fact, that cap, they would be able to continue to provide the current level of services even within that cap.

Mr. RANGEL. Thank you.

Chairman JACOBS. Mr. Gradison.

Mr. GRADISON. No questions.

Chairman JACOBS. Mr. Duncan.

Mr. DUNCAN. I have no questions other than to thank our colleague. I think we are heading in the right direction and we are for the same thing, but perhaps we have different routes to take.

But we do thank you.

Mr. PANETTA. Thank you.

Mr. DUNCAN. Thank you for appearing. I know it will be helpful.

Chairman JACOBS. You heard the comments of Mr. Willging, the average hospitalization was 21 days, and we are talking about two 180-day opportunities for the hospice services.

How say you to that? Do you have any specific response to Mr. Willging's reference to the average of 21 days now in the hospital, vis-a-vis the 180 days eligibility for hospice?

Mr. PANETTA. I frankly would prefer that you ask others that will be testifying before you as to the specifics of comparing the two.

It still seems to me—again, from the studies I have looked at—that those studies have, in fact, considered the average care for a terminally ill patient in the hospital setting and have determined that that is about $7,000, whereas with regards to a hospice patient, it is about $4,400 or $4,500.

I just think that those studies have to be based on facts and statistics, and I would be prepared to go with those because I think it makes a lot of sense.

Chairman JACOBS. He went further to suggest that even with the use of the hospice facility, certain amounts of those 21 days, if for nothing else than the discovery of the malady, could not be supplanted?

How say you to that?

Mr. PANETTA. Say that again, I wasn't clear.

Chairman JACOBS. Mr. Willging made the point that even if an election for hospice care were made, a certain amount of the present cost would remain because of the initial hospitalization, either for examination, discovery of the malady, or for initial hopeful treatment of the malady.

Would you care to say anything on the record in response to that?

Mr. PANETTA. Again, I think that question would be better placed to those that worked on the studies in this area. Again, if the bottom-line figure they come to is that the program is much more cost effective, then I would assume that those considerations have been taken into consideration in the report that they developed.

I guess my point to the subcommittee is that I think it is a very important point that we recognize the ability of the patient to make some choice in this area. We have always imposed upon patients in this country that in order for them to receive the kind of care, they are going to have to do this, they have to be hospitalized, institutionalized, put into this system or that system.

It is about time in this country that we recognize the ability of the patients to make their own decision. If they feel that, in fact, they have been diagnosed as terminally ill, they want the benefits of a hospice as opposed to being institutionalized, that is a choice they ought to have.

Frankly, yes, we ought to consider the cost effectiveness of it. I think that this would prove more cost-effective but I think more importantly, it would improve the ability of individuals to make the kind of choice we ought to be providing the people in this country.

Chairman JACOBS. You have labored long and proud on a thoughtful and useful document, and rather than your expressing gratitude to the committee, the committee should express gratitude to you.

Thank you.

Mr. PANETTA. Thank you.

Chairman JACOBS. Is Representative Courter here?

Apparently not. There are momentous events up in New Jersey, as I understand it.

Mr. GRADISON. Mr. Chairman.

Chairman JACOBS. Mr. Gradison.

Mr. GRADISON. I would ask Mr. Courter's testimony, which we have, be included in the record.

Chairman JACOBS. Without objection, so ordered.

[Congressman Courter's testimony appears at p. 58.]

Chairman JACOBS. Would the first panel please come forward, the National Hospice Organization.

The National Hospice Education project. We have Dr. Olsen, who will introduce the other gentlemen.

**STATEMENT OF EDWIN J. OLSEN, M.D., PRESIDENT, NATIONAL HOSPICE ORGANIZATION, ACCOMPANIED BY DONALD J. GAETZ, CHAIRMAN, NATIONAL HOSPICE EDUCATION PROJECT**

Dr. OLSEN. Mr. Chairman. Thank you, it is a pleasure to be here this morning.

For purposes of introduction, I am Dr. Edwin Olsen, a licensed physician, trained in internal medicine and psychiatry and I am here before you today in my role as president of the National Hospice Organization.

With me is Mr. Donald J. Gaetz, national chairman of the National Hospice Education Project. We are joined by Dr. Mwalimu Imara, director of Methodist Hospital Hospice, Indianapolis, Ind.; Ms. Carmain Siefert, director of Hospice St. Paul in Minnesota; and Dr. Josefina Magno, NHO executive director.

We jointly represent NHO and the National Hospice Education Project and our testimony here today is the unified position of the organized hospice movement in America regarding H.R. 5180.

With your permission, we have submitted for the record additional detail. We will proceed by having Dr. Imara and I orally summarize the joint NHO–NHEP position.

Mr. Gaetz and Ms. Siefert are our designated spokespersons to answer your followup questions.

Hospice in America is essentially a grassroots movement arising both from within and without the traditional health care system.

Chairman JACOBS. As I announced earlier, we have a conflict in our committee schedules here and Dr. Imara, I just wanted to say it is a tradition around here to welcome hometown people and you are indeed welcome.

I have spoken to Dr. Lloyd about your testimony and we welcome it. It will be a part of the record.

At this time, the Chair turns the gavel over to Congressman Rangel.

Dr. IMARA. Thank you very much, Mr. Chairman.

Chairman JACOBS. Dr. Olsen, please proceed.

Dr. OLSEN. Many of America's hospices are related to hospitals, nursing homes, and home health agencies; many are related to freestanding community-based groups.

The vast majority of American hospices are nonprofit in character and behavior, make extensive use of volunteers as well as paid staff on an interdisciplinary team, provide care 24 hours a day, 365 days a year, have particular expertise in physical and emotional symptom control, care for not only the patient, but the patient's family, and emphasize the patient's own home as the primary locus of care with homelike inpatient backup as an integral, but comparatively small component of the whole.

Uncommon in traditional health care, hospice provides care irrespective of the inability to pay—which means that many American hospices are community charities by design and intent—and hospice offers an integrated service functioning not as an add-on, but as a comprehensive alternative to the typical ways of caring for the terminally ill and their families.

In 1978, the National Hospice Organization counted 71 operating hospices in America. Today, NHO identifies 255 provider hospices functioning in all 50 States with at least as many more hospices developing literally in every congressional district in the country.

Yet, irrespective of model or location, the greatest single obstacle to the development and even the survival of hospice in America is the current reimbursement system.

Medicare tends to reward and thus encourage, through present policies of reimbursement and coverage, the highest technology, the highest cost, the most institutionally intensive approaches to care of the terminally ill.

Conversely, the existing medicare system provides significant disincentive and discouragement, through a policy of nonreimbursement, to the hospice alternative and to those who would seek that alternative for themselves and their families.

Clearly, not all dying persons need or want hospice care—no matter the equities or inequities of reimbursement. However, the experience of hospice to date suggests that three-fourths of those persons who are approriate hospice candidates are medicare eligible.

Simply put: since hospice does not presently exist as a separate medicare category with unique service definitions, medicare-eligible Americans who in 1982 need and want hospice care will have to choose not to use hospice services in order to retain their medicare coverage.

Likewise—those who plan and develop health resources in communities throughout America, those who receive and spend medicare dollars, those to whom the care of the terminally ill is entrusted—they must choose not to offer the hospice alternative in order to maximize their Medicare revenues.

Where does the current medicare system leave the hospice movement and the dying medicare beneficiary?

One option is that hospice programs concentrate on caring for persons who do not need to use their medicare coverage to obtain health services—persons of "independent means." In other words, restrict hospice admissions to only those who, after lengthy terminal illness, still have enough ready cash to leave their medicare coverage behind and pay out of pocket for hospice services.

This would amount to consciously shaping the hospice movement to care for the rich—since after a year or two of cancer care costs,

even the middle-class family is as devastated financially as the patient is devastated physically by terminal illness. And, ironically, such a policy of doing nothing now would result in the not so rich and the poor likely dying in expensive, medicare-covered institutions, unable to access the hospice alternative available to the more affluent.

A second option short of passing H.R. 5180 is for hospice programs to wedge themselves into existing medicare reimbursement categories as hospitals, nursing homes, and home health agencies and into existing medicare service definitions.

This approach has been attempted. However, when one tries to be something one is not within the medicare system, some problematic results occur and have occurred within the hospice movement:

One, the delivery of service becomes artificially skewed by an unrelated reimbursement system. It becomes more financially self-serving for a hospice which has worked its way into a medicare certification as, say, a special hospital to act like a special hospital. Since medicare reimburses a special hospital for high-intensity, high-porportion inpatient care, the original concept of hospice as primarily a home-based service loses ground to the seduction of inpatient reimbursement. Terminally ill persons find themselves spending more days in the hospice hospital than at home.

The result of trying to skew hospice into the cure-oriented mold of the existing reimbursement system, instead of establishing a separate reimbursement category and provider accountability, is reimbursement that is too thin for some hospices, too rich for others, and ill-fitting for all.

Unfortunately, by leaving hospice to the vagaries and manipulations of the current medicare system, patient care decisions tend to chase medicare dollars instead of the other way around. Then hospice is no longer an alternative. Not passing H.R. 5180 would endorse and reward such misreimbursement.

Second, if this legislation is not passed and if hospices wishing to care for medicare patients are thereby forced to adjust themselves into existing provider categories, in those States where that is even possible, an incentive is created to inappropriately manipulate care and the records of such care to qualify a nursing visit or an inpatient stay or some other service for reimbursement.

Not passing H.R. 5180 places hospice on shaky ground, courting retrospective disallowances as rewards for hospice care. Not establishing a separate reimbursement category, unique and discreet hospice service definitions, and separate fiscal accountability through a separate provider sets up the hospice movement and individual hospices, for a prosecutorial theory of fraud and abuse.

This is not a distant fear, Mr. Chairman. This is a clear and present danger facing existing hospices today. We urge you to pass this bill.

[The prepared statement and additional material follow:]

STATEMENT OF THE NATIONAL HOSPICE ORGANIZATION IN CONCERT WITH THE NATIONAL HOSPICE EDUCATION PROJECT PRESENTED BY DR. EDWIN J. OLSEN

I am Dr. Edwin J. Olsen, President of the National Hospice Organization. With me is Mr. Donald J. Gaetz, National Chairman of the National Hospice Education Project. We are joined by Dr. Mwalimu Imara, director of Methodist Hospital Hos-

pice, Indianapolis, Indiana; Ms. Carmian Siefert, director of Hospice Saint Paul in Minnesota; and Dr. Josefina Magno, NHO Executive Director. We jointly represent NHO and the National Hospice Education Project and our testimony here today is the unified position of the organized hospice movement in America regarding H.R. 5180.

We have submitted for the Record additional detail. We will proceed by having Dr. Imara and I orally summarize the joint NHO/NHEP position. Mr. Gaetz and Ms. Siefert are our designated spokespersons to answer your follow-up questions.

Hospice in America is essentially a grassroots movement arising both from within and without the traditional health care system. Many of America's hospices are related to hospitals, nursing homes, and home health agencies; many are related to free-standing, community-based groups.

The vast majority of American hospices are non-profit in character and behavior, make extensive use of volunteers as well as paid staff on an interdisciplinary team, provide care 24 hours a day 365 days a year, have particular expertise in physical and emotional symptom control, care for not only the patient but the patient's family, and emphasize the patient's own home as the primary locus of care with home-like inpatient back-up as an integral but comparatively small component of the whole.

Uncommon in traditional health care, hospice provides care irrespective of the inability to pay—which means that most American hospices are community charities by design and intent—and hospice offers an integrated service functioning not as an add-on but as a comprehensive alternative to the typical ways of caring for the terminally ill and their families. A core service of hospice is the provision of bereavement care to families for as much as a year after the patient has died.

In 1978, the National Hospice Organization counted 71 operating hospices in America. Today, NHO identifies 255 provider hospices functioning in all 50 states with at least as many more hospices developing literally in every congressional district in the country.

Yet, irrespective of model or location, the greatest single obstacle to the development and even the survival of hospice in America is the current reimbursement system.

Medicare tends to reward and thus encourage, through present policies of reimbursement and coverage, the highest-technology, the highest-cost, the most institutionally-intensive approaches to care of the terminally ill.

Conversely, the existing Medicare system provides significant disincentive and discouragement, through a policy of non-reimbursement, to the hospice alternative and to those who would seek that alternative for themselves and their families.

Clearly, not all dying persons need or want hospice care—no matter the equities or inequities of reimbursement. However, the experience of hospice in America suggests that three-fourths of those persons who are appropriate hospice candidates are Medicare-eligible.

Simply put: since hospice does not presently exist as a separate Medicare category with unique service definitions, Medicare-eligible Americans who in 1982 need and want hospice care will have to choose not to use hospice services in order to retain their Medicare coverage.

Likewise—those who plan and develop health resources in communities throughout America, those who receive and spend Medicare dollars, those to whom the care of the terminally ill is entrusted—they must choose not to offer the hospice alternative in order to maximize their Medicare revenues.

A decision to forgo or delay passage of H.R. 5180 would not be a benign decision to "keep government from crushing the hospice butterfly," Quite the contrary. Not passing this bill would be an actively destructive perpetuation of a series of reverse cycle incentives and disincentives which today add up to bad policy and bad medicine.

Where does the current Medicare system leave the hospice movement and the dying Medicare beneficiary?

One option is that hospice programs concentrate on caring for persons who don't need to use their Medicare coverage to obtain health services—persons of "independent means." In other words, restrict hospice admissions to only those who, after lengthy terminal illness, still have enough ready cash to leave their Medicare coverage behind and pay out-of-pocket for hospice services.

This would amount to consciously shaping the hospice movement to care for the rich and the very rich—since after a year or two of cancer care costs, estimated to be in the neighborhood of $24,000 per case—even the middle-class family is as devastated financially as the patient is devastated physically by terminal illness. And, ironically, such a policy of doing nothing now would result in the not-so-rich and the

poor more likely dying in expensive, Medicare-covered institutions, unable to access the hospice alternative available to the more affluent.

A second option short of passing HR 5180 is for hospice programs to try to wedge themselves into existing Medicare reimbursement categories as hospitals, nursing homes, and home health agencies and that existing health providers try to contort hospice services into existing Medicare service definitions.

This approach has been attempted. However, when one tries to be something one is not within the Medicare system, some problematic results occur and have occurred within the hospice movement:

1. *The delivery of service becomes artificially skewed by an un-related reimbursment system.* It becomes more financially self-serving for a hospice which has worked its way into a Medicare certification as, say, a special hospital to *act* like a special hospital. Since Medicare reimburses a special hospital for high-.intensity, high-porportion inpatient care, the original concept of hospice as primarily a home-based service loses ground to the seduction of inpatient reimbursement. Terminally ill persons then find themselves spending more days in the "hospice hospital" than at home.

The results of trying to skew hospice into the cure-oriented mold of the existing reimbursement system, instead of establishing a separate reimbursement category and provider accountability, is reimbursment that is too thin for some hospices, too rich for others, and ill-fitting for all.

Unfortunately, by leaving hospice to the vagaries and manipulations of the current Medicare system, patient care decisions tend to chase Medicare dollars instead of the other way around. Then hospice is no longer an alternative. Not passing HR 5180 would endorse and reward such mis-reimbursement.

2. If this legislation is not passed and if hospices wishing to care for Medicare patients are thereby forced to gerrymander themselves into existing provider categories, in those states where that is even possible, an incentive is created to inappropriately manipulate care and the records of such care to qualify a nursing visit or an inpatient stay or some other service for reimbursement.

Not passing H.R. 5180 places hospice on shaky ground, courting retrospective disallowances as rewards for hospice care. Not establishing a separate reimbursement category, unique and discreet hospice service definitions, and separate fiscal accountability through a separate provider number—not doing that sets up the hospice movement and individual hospices, especially those based in hospitals or home health agencies or nursing homes, for a prosecutorial theory of fraud and abuse.

This is not a distant fear, Mr. Chairman. This is a clear and present danger facing existing hospices today.

We urge you to pass this bill, Mr. Chairman, and pass it in its present form.

Why?

First, because H.R. 5180, in its present form, captures the best and most reliable experience of the American hospice movement as to the needs of the terminally ill and the methods hospices are using and should use to meet those needs.

Over most of the past decade, the National Hospice Organization has had underway continual interdisciplinary study and evaluation of hospice principles and practices in this country. The formal result of that painstaking effort has been the National Standards of Hospice Care. Upon these Standards have been built the private and public hospice benefit plans and state hospice laws in this country. Submitted with our written testimony is a copy of these Standards.

A careful examination of the National Standards for a Hospice Program of Care will show that H.R. 5180 embodies what hospice care is and what it ought to be at the patient/family level including such important matters as medical direction, the insistence upon hospice as a home-based service, the functional necessity for hospice to be separately certified, the voluntary component, and the need for the core services to be provided by the hospice interdisciplinary team.

If HR 5180 is passed in its present form, it will not be the reimbursement system defining hospice in a restrictive way, but, rather, it will be the needs of the dying and their families defining the reimbursement system in a way consistent with the mainstream of the hospice movement in America.

The second reason why it is this bill that we favor is because H.R. 5180 has the overwhelming support of the people who deliver hospice care throughout this country. The National Hospice Organization, through the near-unanimous vote of its board of directors and in response to the mandate of its membership, is united with the National Hospice Education Project in urging you to pass this bill, in this form, undiluted, and without delay.

Why now? Why pass this bill this year instead of waiting?

For three reasons.

1. Between today and a year from today, at least 50,000 and perhaps as many as 100,000 Americans for whom hospice may be appropriate will live out their final months. Many will suffer chronic, excruciating pain and other noxious symptoms unsuccessfully controlled in the traditional health care system. Each of these Medicare-eligible Americans will, according to one study, spend 21 of the last 60 days of life in acute care hospitals subjected to batteries of expensive medical-surgical heroics and artificial life support systems the net result of which will be to neither lengthen life nor improve its quality. And the final irony, Mr. Chairman, is that what will happen to these Americans will be desired neither by them, their families, nor their attending physicians.

We who work in hospice think and work in getting the most out of days or even hours. Many Medicare-eligible Americans will pass many hours and days of terminal illness in the next year.

I hope you will excuse me for saying that these Americans and their families will gain nothing and lose everything if you wait another year.

2. The hospice movement, itself, will be severely affected by more delay. The National Hospice Organization is painfully aware that many leading American hospices will either close down or fold back if the injustices and inequities in the reimbursement system are not rectified without delay. As those hospices are closing—and they are closing even now—their patients and potential patients are being thrown back into the curative care system—costing Medicare money.

3. There is no reason to delay because the case for support to pass this bill this year is already convincing and persuasive. Years of research and groundwork have gone into this legislation.

There will always be hospice studies underway and there should be. Some were completed last month. Some will be completed next month, some next year, some three years from now. To date, more than forty public and private, government and non-government hospice demonstration studies and cost analyses have been undertaken. Yet, without exception, every single one shows that when hospice is substituted for the already-covered array of Medicare services, there is nearly always a net savings and nearly never a net cost.

The current HCFA hospice study is one example of a valuable study which has already given us excellent service definitions—but which started late, didn't put the evaluation component in place until a year after the study had already begun, focused out and isn't even considering any study of reimbursement methodology, and has already been subjected to many of the same difficulties accompanying similar HCFA studies.

We believe that the HCFA hospice study, assuming it is completed according to the very optimistic schedule heard today, will be concluded just in time to substantially assist the regulatory sector in implementing H.R. 5180. There is no doubt that the HCFA study and those associated with it have been of benefit to this entire effort.

However, passage of the legislation should not be held hostage to the HCFA study.

Mr. Chairman, we recognize that legislative language cannot answer every finite question and every local peculiarity within the hospice movement. In fact, we are extremely pleased that H.R. 5180 gives substantial flexibility to the varying models of hospice care and to the creative evolution of the hospice alternative in urban and rural settings. We are likewise pleased that the legislation takes strong stands in those areas which describe hospice's uniqueness.

It is in that spirit that we offer you our best efforts not only to pass this bill, but to make it work when it passes. We are reassured that the principal sponsors of this bill are committed to seeing that hospice input, from the grassroots of the hospice movement as well as through the NHO committee structure, will be welcomed in the implementation of H.R. 5180.

You will hear considerable testimony on this bill, both oral and written. I know you will give all of it due weight. However, I urge you to remember that to make a difference, hospice must be different and that the integrity of this concept and the needs of the dying should take a higher priority than the interests of any single provider or provider group.

In hospice, the patient and family become integral parts of the caring team. The actions and decisions of the caregivers are oriented to the needs and convenience of the patient and family. Let that be your criterion today. As you listen to those who will testify, ask yourself: for whom do they really speak?

To decide not to pass this bill would not be a neutral decision. It would be a negative decision perpetuating inequities in reimbursement, discriminating against the hospice alternative, and effectively denying hospice care to many Americans who

cannot afford to leave their Medicare eligibility behind when they seek health services.

To pass this bill would be to take into account and thoughtfully affirm eight years of experience in studying and developing the hospice benefit you see before you today in the form of H.R. 5180.

To pass this bill would be to establish and recognize the hospice alternative, while taking us at our word that hospice is, overall, less expensive than the options you are already paying for under Medicare. To pass this bill is to hold us to the test of proof that we are what we say we are.

Passing this bill would not add a single new person to the Medicare rolls; but would give those who are already eligible an opportunity to choose perhaps a more appropriate, perhaps a more competent, perhaps a less expensive alternative.

There is a hospice chaplain, Reverend Ron Mudd, who is now himself a cancer patient. He frames the essence of this legislation and the essence of what we are doing this way:

"There are times when medical science, despite all its skills and buildings and equipment, simply cannot add more days to people's lives. It is then that hospice can add more life to their days."

Mr. Chairman, thank you very much.

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ADDITIONAL WRITTEN TESTIMONY RE: H.R. 5180—DR. EDWIN J. OLSEN, M.D., PRESIDENT

The Hospice concept is founded upon a principle that the terminally ill patient and his family should have an alternative means of care when modern medical technology is no longer able to offer any reasonable hope for curative treatment. But the lack of an alternative to intensive, curative treatment has forced hundreds of thousands of patients and their families into agonizing experiences relating to the financial, social, and mental stress associated with terminal illness in America. Much of the damage done to families in such situations may remain after the patient dies.

Concern for the total family is part of what makes Hospice care different from traditional forms of health care. Ideally, the patient should be given the option to be cared for at home by the family, and, if appropriate allowed to die there. To this end, Hospice teams assist the family not only in providing care but also in coping with the effects of the illness and ultimate loss.

The Hospice team, in support of the patient's physician, can help the dying patient and his family confront their problems, adjust to them and concentrate on achieving quality in the dying person's remaining lifetime. Additionally, the Hospice concept concentrates upon important functions of controlling pain and other distressing disease symptoms, such as breathing difficulties and nausea. Hospice care is the most effective realization of humanization of care thus far found in the health care delivery system of the United States.

Hospice programs advocate that patients should be as sympton-free as possible in order to use their energies for living. The interdisciplinary approach encompasses not only physicial pain but psychological, spiritual, and social pain as well. The latest pharmacological capabilities and other modalities are utilized to keep the patient as free of pain as possible while remaining alert and functional. Hospice programs operate 24 hours a day, seven days a week, to ensure that help will be available whenever a patient or family member is in need of care or support.

The Hospice concept, itself, is not new. Since medieval times special groups have existed to care for the sick and wounded. But as more recent medical technology emphasized disease entities and clinical practice, the Hospice concept of total care waned in prominence. With the rising incidence of cancer and other terminal conditions in America, there is a need for a return to humanistic treatment for the terminally ill and their families. The Hospice movement is a direct attempt to meet human needs in the face of adversity.

THE NATIONAL HOSPICE ORGANIZATION

The Hospice movement in Ameirca was formally structured with the formation of the National Hospice Organization (HNO) in May , 1978. Such issues as the rising incidence of terminal illnesses, the burden of long-term, non-curative care on the medical community, the financial impact of long-term care for terminally ill patients and their families, the need for bereavement counselling of patient's families and many other current-day dilemmas of terminal illness forces the attention of countless individuals, both laymen and professionals, on the need for alternative more humane and effective solutions.

Through innumerable hours of massive volunteer contributions, the national organization began an effort to unify the multitudes of interested parties and organizations. As with any new, growing movement, the coordination of efforts and interests took on new and increasingly important meaning.

Through a totally volunteer effort, the first Hospice Symposium was convened in October 1978. Participants numbered over 1,200 from across the Nation, all vitally interested in developing a system or better health care for the terminally ill.

At the first NHO Symposium, the participants adopted their official character, elected a volunteer Board of Directors and established the following statements of organizational purposes:

Develop a clear understanding of the Hospice concept among health care professionals as well as the public.

Provide for a steady flow of information and communication among existing Hospice groups, and others that are evolving.

Develop and maintain standards of care in program planning and implementation.

Provide technical assistance to Hospice organizations in their formative years, and evaluation of their programs.

Make available basic training materials to assist new groups, their boards, members and volunteers.

Monitor health care legislation and regulation at all governmental levels relevant to the Hospice movement.

Additionally, the following statements of immediate goals and objectives were adopted:

Define a common data collection base to be used for the purpose of demonstrating definite national trends in the care of the terminally ill and their families.

Design policy to be considered by the legislators and governmental agencies for provision of care for the terminally ill and their families.

Develop standards and procedures for giving accreditations to Hospice organizations.

Provide opportunities for training through workshops, seminars and other similar programs.

In order to achieve these objectives, NHO created Committees which will address major areas of concern which directly affect these goals. During the years from 1978 to 1981, these Committees have evolved as follows:

1. Standards and Accreditation,
2. Research and Evaluation,
3. Education and Training,
4. Professional Liaison,
5. Finance and Development,
6. Bylaws and Membership,
7. Nominating,
8. Ethics,
9. Public Relations,
10. Annual Meeting.

In addition, there are the President's Ad Hoc Committees on

1. Personnel Policies.
2. Insurance.

To insure that the Committees have direct access to the NHO Board, a Board member is designated to each Committee as Board Liaison and he/she functions as a member of the Committee. The functions of the Committees are described in the Bylaws of the National Hospice Organization.

### NEED FOR LEGISLATION

While the first Hospice Program started delivering care to terminally-ill patients in the United States only in 1974 (now the Connecticut Hospice) the number of hospice programs has increased very dramatically during the past eight years. Today there are anywhere from 800 to 1,000 hospice programs in varying stages of development in every state of the U.S. Many of these hospice programs are well organized and deliver both home care and inpatient care. Some of them are small programs in urban and rural communities and are merely home care programs. What this situation demonstrates is the fact that the health care system needs to provide an alternative way of caring for terminally-ill patients that is not presently being met by the conventional health care system. Hospice care provides this alternative and enables the dying patient and his family to receive the support that they all need to make this part of life meaningful.

Ninety-five percent of hospice patients today are cancer patients because it is the cancer patient who conforms best to the criteria for admission into a hospice program of care, i.e., 1) a prognosis of six months or less and 2) a certification by the patient's physician that curative treatment is no longer indicated.

National statistics show that every cancer patient spends approximately $23,000 from the day of diagnosis until the time of death, a period of roughly two years. This presupposes that most patients who are terminally ill of cancer and who are in need of hospice care are not in a position to pay for this type of care. Because hospice care is competent, appropriate and compassionate care, a hospice team is composed of competent specialists and well-trained volunteers who together are able to meet the needs of the patient and family. This quality hospice care recognizes that hospices be provided with reimbursement for services they render, a reimbursement that does not presently exist in the health care system. Legislation is, therefore, of crucial importance if hospice care is to continue being provided to dying patients in the U.S.

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## Standards of a Hospice Program of Care

(Adopted by the Board of Directors of the National Hospice Organization, November 1981)

### DEFINITION OF A HOSPICE PROGRAM OF CARE

A Hospice is a program of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families. Services are provided by a medically supervised interdisciplinary team of professionals and volunteers. Hospice services are available in both the home and an inpatient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and around-the-clock on-call basis. Bereavement services are available to the family. Admission to a Hospice program of care is on the basis of patient and family need.

### HOSPICE PHILOSOPHY

Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortable as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

### ADMINISTRATION

Principle: The health care delivery system, of which hospice program is an integral part, is regulated by local, State and Federal law. In order to provide care in this system, a hospice program must meet the fundamental requirements for operation and delivery of service.

Standard 1: The hospice program complies with applicable local, State and Federal law and regulation governing the organization and delivery of health care to patients and families.

### CONTINUITY OF CARE

Principle: Hospice patients and families may experience a considerable degree of fragmentation and alienation. Hospice maintains that continuity of care (including both services and personnel) reduces the sense of fragmentation and alienation. "Continuity" implies the capacity to respond to patient/family needs whenever they arise. It also implies enough administrative and staff integration to ensure continuation of the same high quality care when the patient moves from home to inpatient unit or vice versa.

Standard 2: The hospice program provides a continuum of inpatient and home care services through an integrated administrative structure.

Standard 3: The home care services are available 24 hours a day, seven days a week.

PATIENT/FAMILY AS THE UNIT OF CARE

Principle: Inclusion of the family in the hospice care program is essential. The wishes and desires of the patient/family are of central importance in developing the care plan. The family members are seen both as primary caregivers and as needing care and support so that their own stresses may be attended to. Attention is also paid to developing a quasi-family support network when relatives are not available and a patient needs and wants that support.

Standard 4: The patient/family is the unit of care.

Standard 5: The hospice program has admission criteria and procedures that reflect:

A. The patient/family's desire and need for service,

B. Physician participation,

C. Diagnosis and prognosis.

The hospice program encourages family participation in patient care and provides support for them.

Standard 6: The hospice program seeks to identify, teach, coordinate and supervise persons to give care to patients who do not have a family member available.

Standard 7: The hospice program acknowledges that each patient/family has its own beliefs and/or value system and is respectful of them.

PERSONNEL

Principle: The amount and type of care is based on need, as established with the patient and family. Care is provided by an interdisciplinary staff which includes at least the following qualified personnel (core team): Patient and patient's family, physician, nurse, social worker, volunteer, clergy. The team is coordinated by a qualified health care professional. The team meets regularly to develop and maintain an appropriate plan of care and to determine which staff members will intervene and work together in a situation. Regular staff support, education and training are also provided, based on recognized need.

Standard 8: Hospice care consists of a blending of professional and nonprofessional services, provided by an interdisciplinary team, including a medical director.

Standard 9: Staff support is an integral part of the hospice program.

Standard 10: Inservice training and continuing education are offered on a regular basis.

SYMPTOM CONTROL

Principle: Hospice programs recognize that when a patient and family are faced with terminal disease, stress and concerns may arise in many aspects of their lives. Optimum symptom control includes addressing those stresses and concerns, in addition to the use of appropriate therapies. This therapy may be a blend of curative and palliative treatments that produce the greatest degree of relief from stress caused by disease for the longest period of time, with the least undesired side effects.

Standard 11: The goal of hospice care is to provide symptom control through appropriate palliative therapies.

Standard 12: Symptom control includes assessing and responding to the physical, emotional, social and spiritual needs of the patient/family.

BEREAVEMENT

Principle: Grief and bereavement are normal reactions to loss and death. Grief is the highly personal response to loss; bereavement is the extended period of deprivation following the loss of a loved one. Grieving may precede an anticipated death or may be delayed for a considerable time. Grief may manifest itself in emotional and/or physical distress and may affect different family members in different ways at different times. Death of a family member can result in a wide range of physical, emotional, social, familial, economic and spiritual disruptions. Some persons can resolve grief with time and their own available resources; others may require formal assistance and support over an extended period of time.

Hospice work includes attention to needs of the bereaved, to assessment of needs of the bereaved, both before and after a death, and to the development of programs and resources to meet the needs of the bereaved. Hospice encourages the expression of grief, recognizes social/religious and ethnic variables in bereavement and supports staff and family participation in meaningful funeral services and rituals.

Standard 13: The hospice program provides bereavement services to survivors for a period of at least one year.

QUALITY ASSURANCE

Principle: Hospice is committed to developing and utilizing methods to measure and asure quality of patient/family care.

Standard 14: There will be a quality assurance program that includes:

A. Evaluation of services,

B. Regular chart audits,

C. Organizational review.

RECORDS

Principle: Documentation of services is necessary and desirable in the delivery of quality care. Therefore, a hospice record of care will be maintained in order to insure compliance with regulatory and quality care standards. Of critical importance is the development of an integrated chart which records the assessments and proposed interventions by all interdisciplinary team members for the patient as well as for the family.

Standard 15: The hospice program maintains accurate and current integrated records on all patient/families.

PHYSICAL PLANT

Principle: Not all patients can be maintained at home; some require inpatient services. The hospice inpatient unit reflects the unique nature of hospice care, and provides for special needs of the dying and their families.

Standard 16: The hospice complies with all applicable State and Federal regulations.

Standard 17: The hospice inpatient unit provides space for:

A. Patient/family privacy,

B. Visitation and viewing,

C. Food preparation by the family.

GLOSSARY

*appropriate*—especially suitable or compatible; fitting.

*bereavement*—the period of time during which a person or group of people experiences, responds emotionally to, and adjusts to the loss by death of another person. Hospice is attendant particularly to the acute phase of the bereavement process, usually occurring within the first year after the loss.

*care*—to perceive and respond to the needs of another.

*clergy*—the body of persons ordained for religious service.

*continuum*—the uninterrupted provision of services appropriate to the needs of the patient and family; these services are planned, coordinated, and/or made available by the Hospice program.

*coordinate*—to organize and manage the efficient utilization and interaction of multiple resources.

*core team*—the essential members of the core team include the patient and family unit, physician, nurse, social worker, clergy, and volunteer who work together as an interdisciplinary team to provide Hospice care.

Note: the physician on the core team may be the primary physician and/or the Hospice physician.

*family*—a group of individuals living under one roof and under one head; a group of persons of common ancestry; a group of individuals having a common commitment one to the other.

*grief*—response to loss that often occurs in stages of varying length. These stages are differentiated by changes in feeling, thought, and behavior following loss. The stages can but do not always occur in a predictable order.

*interdisciplinary*—a term describing the Hospice team, indicating that the team members, representing the core disciplines and other related disciplines, interrelate in an effective working relationship enabling the provision of Hospice services to Hospice patients and their families.

*licensed*—persons authorized to practice in the professional discipline for which they have been prepared by the licensing authority having jurisdiction in the state of their operation.

*limited prognosis*—the disease state that has minimal chance of reversal and for which the remaining life span is estimated to be six months or less.

*medical director*—that licensed medical practitioner (salaried or not) on the Hospice staff who has been identified by the Hospice team as having ultimate responsi-

bility for medical aspects of Hospice care. This individual can be directly or indirectly involved in actual patient care.

*nurse*—a graduate registered professional in the nursing field who is involved with the determination and delivery (directly or in an advisory capacity) of nursing aspects of Hospice care to patients and families on the Hospice program.

*nursing*—is primarily assisting individuals (sick or well) with those activities contributing to health or its recovery (or a peaceful death) that they perform unaided when they have the necessary strength, will or knowledge; nursing also helps individuals carry out prescribed therapy and to be independent of assistance as soon as possible. (Henderson, Virginia: *Principles and Practice of Nursing,* sixth edition, Macmillan Publishing Company Co., Inc., 1978, p. 14.)

*nursing service*—pertaining to the curative, rehabilitative, and preventative aspects of nursing care that are planned, performed, supervised, and/or directed by a registered professional nurse (from the *Classification of Health Care Institutions,* published by the American Hospital Association, 1974).

*palliative treatment*—the primary dictionary meaning of the term "to palliate" is "to reduce the violence of; abate." In the Hospice context, it means the reduction or abatement of pain and other troubling symptoms by appropriate coordination of all elements of care needed to achieve relief from distress.

*physician, attending*—any licensed medical practitioner identified by the patient and family as having a significant role in the determination and delivery of medical care while on the Hospice program. This individual usually would be the primary physician, but would not usually be part of the Hospice staff.

*physician, consulting*—any licensed medical practitioner asked by medical practitioners already treating a patient and family to provide limited medical advice and therapy for the specific needs of a patient or family. Such care is provided under the coordination of the requesting physician, who may or may not be on the Hospice staff.

*physician, Hospice*—any licensed medical practitioner on the Hospice staff (salaried or not) who is involved with the determination and delivery (directly or in an advisory capacity) of medical aspects of Hospice care to patients and families on the Hospice program. This individual may or may not be the patient's primary physician.

*physician, primary*—that licensed medical practitioner whom the patient and famly identify as having the most significant role in the determination and delivery of medical care to the patient at the time of referral to and acceptance on the Hospice program. If this physician is not on the Hospice staff, the physician's consent will be necessary for admission of the patient to the Hospice care program.

*plan of care*—the orderly and detailed design and method for expressing concern and taking responsibility for another—in this case, the patient and family unit.

*primary care person*—that member of the family who is designated by the patient and the Hospice care team as the chief or leading giver of care to the patient at home.

*record*—a written documentation that accurately reflects all elements of patient care including assessment, planning, intervention, and evaluation.

*social work*—the professional activity of helping individuals, groups, or communities enhance or restore the capacity for social functioning and creating societal conditions favorable to this goal. Social work practice consists of the professional application of social work values, principles, and techniques to one or more of the following ends: helping people obtain tangible services; psychotherapy with individuals, families, and groups; helping communities or groups provide or improve social and health services; participating in relevant legislative processes. The practice of social work requires knowledge of human development and behavior; of social, economic and cultural institutions and of the dynamics of the interactions of all these factors. (National Association of Social Workers).

*social worker*—one who possesses a master's degree in social work from a college or university accredited by the Council on Social Work Education. Hospice social work services may be managed or delivered by a person possessing a bachelor's degree in social work from a college or university accredited by the Council on Social Work education as long as that person maintains a regular, ongoing, consultative relationship with a graduate social worker.

*special needs*—those requirements which are particular to the situation or condition of a Hospice patient and family.

*special services*—those services not represented on the core team that may be valuable for specific patient and family needs, including but not limited to, homemakers, home health aides, recreation therapists, occupational therapists, respiratory therapists, pharmacists, dieticians, lawyers, certified public accountants, funer-

al directors, musical therapists, art therapists, speech therapists, physical therapists. The motivation for inclusion of such services is to enhance the patient's and families abilities to deal with the special stresses of specific situations.

*standard*—an authorized principle or rule that usually implies a model or pattern for guidance by comparison with which the quality, excellence, or correctness of other things may be determined.

*terminally ill*—experiencing an illness for which therapeutic strategies directed toward cure, outside the context of symptom control, are no longer appropriate; expected survival of six months or less.

*unit of care*—who it is that is to receive Hospice services; since the term "unit" means a single, whole "thing", Hospice defines the patient and family to be the single whole, regardless of the degree of harmony or integration of the parts within that whole.

*volunteer*—that lay or professional person who contributes times and talent to the Hospice program without economic remuneration.

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STATEMENT OF DONALD J. GAETZ, NATIONAL CHAIRMAN, NATIONAL HOSPICE EDUCATION PROJECT

Mr. Chairman, the National Hospice Education Project is grateful for your allowing us to submit testimony regarding H.R. 5180, "The Hospice Reimbursement Act." We compliment the Chairman, the Members of the Subcommittee, and, certainly, the Subcommittee Staff for the thoroughgoing and thoughtful manner in which they have proceeded to analyze the need for legislative remedy to the problems which dying Americans have in appropriately utilizing their Medicare benefits.

The National Hospice Education Project is an ad hoc coalition of more than six hundred non-profit, community-based organizations engaged in the care of dying Americans and their families. The Project includes the vast majority of provider hospices affiliated with the National Hospice Organization plus an equal number of other hospices, hospitals, home health agencies, and nursing homes not affiliated as provider members of NHO. The National Hospice Education Project reflects the richness and diversity of the hospice movement, its national flavor, and the special problems and concerns of varying providers operating in sparsely-populated rural counties to those managing the complexities of home and inpatient care delivery in major urban centers.

Associating with the National Hospice Education Project are major private philanthropic interests as well as Fortune 500 corporations, HMO's, national religious denomination task forces, and the Washington Business Group on Health.

In nearly two years of study and research, we have determined that the continued bona fide development and survival of the hospice movement is fundamentally threatened by a health care reimbursement system prejudiced in favor of the highest-cost, most institutionally-intensive, acute care approaches to the needs of the terminally ill.

Though hospice programs of care have been providing services to patient/families for eight years in this country, amassing a wealth of public and medical professional testimony as to the quality and appropriateness and cost-effectiveness of care, hospice, per se, is not recognized as an alternative category of care within the Medicare system.

The National Hospice Education Project has extensively explored the problems this lack of recognition poses and potential policy options.

PERMANENT AND TOTAL DISABILITY—NOT AN OPTION FOR HOSPICE PATIENTS

The Social Security system does provide a pension and eventual access to health care benefits for persons declared to be permanently and totally disabled.

What could be more permanently and totally disabling than dying?

Yet, under current provisions of law, for a dying person to access this route to care, he or she has to out-live a waiting period of up to two years before collecting benefits. The typical hospice patient in this country is deemed appropriate for hospice services with a terminal prognosis of six months or less. Practically, the experience of most hospice programs shows an average term of care (number of calendar days between hospice admission and death) of 70 to 90 days.

In other words, the existing permanent and total disability section of the law is not a useful tool for a hospice patient. By the time a typical hospice patient would qualify, he or she would have been dead for weeks or months. In any case, the primary need of a terminally ill person is probably not a government pension. The need is for competent, compassionate health care.

Declaring all terminally ill Americans with a prognosis of six months or less to be permanently and totally disabled at the time of such prognosis and thereby entitled to use Medicare benefits to obtain hospice services is a policy option considered by the National Hospice Education Project.

The Bayh Amendment, which passed the Senate in 1979, would have approximated this option with some modifications. Cost implications, however, precluded full congressional approval. More to the immediate point, however, the Bayh Amendment would have created a whole new set of entitlements. Perhaps the nature of the hospice movement would have changed, as well, making hospices into "hundred percenters" vis a vis the Medicare system, fashioning the hospice movement into a regrettable replica of some regrettable sections of the home health industry, and undermining the voluntary and grassroots nature of hospice in America.

While well-intentioned, the Bayh Amendment route would serve neither the stability of the Social Security system nor the integrity of the hospice movement nor the needs of the terminally ill and their families.

### THE CURRENT MEDICARE SYSTEM: AN ACTIVE DISINCENTIVE AGAINST HOSPICE

The current Medicare system treats hospice as non-existent, despite the fact that literally hundreds of communities throughout America have evidenced both the need and the capacity for the rendering of hospice care.

What is the harm in Medicare not recognizing hospice as a separate category of care?

The result of the present Medicare policy is that the federal government is, in effect, saying to the terminally ill patient and his or her family:

"If you will choose acute care, including hospitalization at a cost of $300 to $1,000 per day, the federal government will be responsibile on your behalf for paying what providers will accept as full payment for your care.

"If you choose hospice care, we may or may not pay a portion of the bill, depending upon the sophistication of the hospice in skewing its services into existing reimbursement categories; but you can never expect us to arrange for 'full payment'."

It takes little imagination to conclude that only a dying person of independent means who can afford to leave Medicare eligibility behind when choosing health care will be much benefited from such a reimbursement policy.

The same current Medicare system says to the provider of health care services:

"If you will admit the dying person into the hospital, perform the usual routine admission tests, place the patient in an acute care bed or even an intensive care setting order enough repetitive diagnostic work-ups and perhaps even some additional surgery to help justify the stay . . . then we will reimburse you on the highest level of reimbursement.

"If, however, should you devote yourself and your organization to palliating the patient's symptoms, eschewing additional medical-surgical heroics that will neither lengthen life nor improve its quality, developing and additional medical-surgical heroics that will neither lengthen life nor improve its quality, developing and sustaining a support system in the patient's home sufficient to care for the patient and educate and reassure the family, and providing 365-day, 24-hour care including intervening with home visits at 4 a.m. to avoid an unnecessary hospitalization . . . and if you respond to the occasional need for inpatient care with a home-like, noninstitutional setting high on caregivers but low on technology . . . if you do all that under the rubric of hospice, then the federal government will reward you with little or no reimbursement, at all."

"What's more, you, as a provider, may be committing fraud or abuse by even billing for and accepting what reimbursement you can get because the word 'hospice' doesn't represent a category that's in our rule book yet."

In essence, Mr. Chairman, the federal government, through its Medicare program has chosen to provide a federal stubsidy to one form of terminal care—acute care—and to thereby provide a federal disincentive for Medicare patients to utilize hospice care.

A provider of health care services penalizes itself financially when making hospice services available instead of keeping dying patients in the traditional cycle of more and more aggressive therapies yielding less and less effective results. That is the current state of affairs.

THE RESULT OF DOING NOTHING: LEGAL AND FRAUD/ABUSE IMPLICATIONS

(Attorney David H. Eisenstat, speaking before the National Hospice Leadership Seminar outlined the legal bind which the current reimbursement system places hospice programs in . . . a bind that cannot be solved within existing reimbursement categories)

Eisenstat states:

"To the extent that Hospice programs have been successful in obtaining third-party reimbursement thus far, they have done so by isolating certain service components of hospice care which are arguably included under the existing inpatient and/or home health care coverage of traditional reimbursement schemes. This mode of reimbursement, I believe, is premised upon a fundamental fiction—the discrete hospice service components for which reimbursement has been traditionally made and the manner in which these components fit into the total hospice program of care, are radically different from the covered services and program design of the traditional curative-oriented health care system. This "round-peg-in-a-square-hole" approach to reimbursement does not, in my estimation, represent a viable long-term solution to the problem of reimbursement for hospice care for a variety of reasons."

"First, there are elements of hospice care which, even under the most expansive view, simply cannot be plugged into any category of traditionally covered benefits—bereavement counseling, family education, transportation, and respite-type inpatient care come immediately to mind in this connection. No existing health care payment plan of which I am aware defines the "patient" as both the 'patient and family unit.'

"In this particular regard, there are a variety of provocative questions which remain to be answered concerning the scope of the covered family unit and the length of time following a patient's demise during which counseling services to the family unit will continue to be covered."

"Second, by associating with a cure-oriented health care delivery system, the hospice program may become saddled with costs bearing little or no relationship to hospice care. This is particularly true for hospice programs associated with acute care or skilled nursing facilities where traditional step-down cost allocation methodologies necessitate that an array of costs appropriate to the acute setting, particularly administrative and general costs, be shared by the hospice program. Under traditional reimbursement accounting principles, when costs flow into unequal users and cannot be allocated by use, certain institutional users of necessity bear more than their fair share of costs. This situation unavoidably applies to hospices associated with acute care and skilled nursing facilities. It is no solution to this particular problem to merely formulate a different level of payment for the hospice bed located in a hospital—a rate presumably reflecting more accurately the costs of providing hospice care as opposed to acute care in that setting. The obvious shortcoming of this approach is that it would unavoidably under-reimburse the acute-care side."

"Although all the evidence is not yet in, I strongly suspect that ultimately, the most cost-effective way of providing complete hospice care is through the free-standing hospice facility with its own inpatient bed complement as well as home health care and other hospice capabilities. I cannot see the sensibility of charging a hospice program for the use of an inpatient bed at the same per diem rate as is charged for acute care use—the type care provided in the two settings is radically different and, logically, the attendant expenses should also be different. However, unless the hospice program effectively unbundles itself from the hospital or nursing home reimbursement schemes, the true cost experience of hospice care can never be identified."

"My third area of concern, and perhaps the most unsavory, is the potential for fraud and abuse in reimbursement. Although this particular issue has not been widely addressed in connection with hospice, it deserves our serious attention. Payment scandal is the last thing the hospice movement needs at this stage of its development."

"As a result of existing legislation intended to discourage Medicare and Medicaid fraud and abuse, the health care industry, including the hospice movement, must be highly sensitive to the civil and criminal implications of a variety of activities which in the past have been approved, or perhaps even encouraged, within the industry by third-party payers. The legislation to which I refer is generically known as the Medicare-Medicaid Anti-Fraud and Abuse Statutes (originally enacted in 1972 and subsequently amended in 1977 as P.L. 92-603 and P.L. 95-42). This statutory scheme, among other things, broadly prescribes a range of activity in connection with the furnishing of items or services for which payment may be made under

Medicare and Medicaid. Specifically, there are substantial fines and/or imprisonment for knowingly and willfully making or causing to be made any false statement or representation in any application for benefit or payment, or in connection with conditions of participation in programs.

"HEW's Office of Program Integrity, which is responsible for identifying and investigating instances of Medicare fraud and abuse, has already declared its intention to focus vigorous new investigatory and prosecutorial initiatives upon providers. Similarly, reports of state-level investigations of Medicaid fraud and abuse have become commonplace. Felony convictions under these enforcement schemes can result in fines of $25,000 and imprisonment for up to five years for each offense.

"How does fraud and abuse effect hospices specifically? In one sense, hospices are impacted in much the same way as any other provider, and in this respect, potential problems may arise in any number of ways. For example, each time a Medicare or Medicaid patient complains that he or she did not receive a particular injection or see a physician as indicated on the patient's bill, there is a problem inviting investigation. When allegations of this sort are proven and the billing entries were made knowingly, there may be violation of the statute's fraud provisions. Even when inadvertent, such entries may result in allegations of program abuse. As an aside, the line between fraud as opposed to abuse is, to say the least, a narrow one—one government official defined the term 'abuse' as any practice he didn't like but doubted he could obtain a 'fraud' conviction for. I've even heard 'abuse' defined for purposes of the statute as reimbursement maximization. The point is that there statutes provide a great deal of prosecutorial discretion, and as a hospice provider—running a novel program with a high degree of public visibility—I would be extremely wary of exposing myself to the whims of zealous government prosecutors (of which there are many).

"Hospice programs may be uniquely vulnerable to investigation and prosecution. To the extent that hospices have sucessfully garnered reimbursement in the past, they have done so largely by defining components of hospice care along the dimensions of existing covered services. This 'round-peg-in-a-square-hole' approach to reimbursement, which I described earlier, may arguably give rise to a prosecutorial theory of fraud or abuse. My concern is that an aggressive and innovative prosecutor could turn a critical eye upon program payments received in the past by hospice programs and make out a convincing case that the narrow line between covered service and nonallowable cost has been unlawfully breached."

"One need look no further than the list of waivers under the HCFA demonstration program for examples of potential fraud and abuse vulnerability. If I were prosecutor, I could not help but ask: 'How has reimbursement been obtained in the past without the waivers?' Additionally, a recent survey of Blue Cross Plans turned up evidence that a substantial number of hospice-type services have been traditionally reimbursed as a part of general administrative and overhead costs, rather than as specific line items. This effective 'burying' of hospice-type costs, albeit perhaps with the tacit endorsement of third-party payers, has a significant potential for fraud and abuse prosecution."

"The clear implication of what I've had to say is that the development of a separate reimbursement system for hospice is critically needed—a system which is independent of the reimbursement systems of hospitals and nursing homes. Until hospice reimbursement achieves this separate status, problems of excessive cost and fraud and abuse will persist. To achieve this end, a major legislative effort will be necessary. I believe such an effort can, if properly conducted, be ultimately successful. This effort must be a united effort—individual hospices cannot go on arranging private deals with third-party payers to suit their idiosyncratic needs."

### H.R. 5180: A REVIEW OF ITS IMPLICATIONS

This conservative proposal would amend the Social Security Act to allow currently Medicare eligible persons to use their existing benefits to obtain services from bona fide hospice programs of care. The hospice movement would have the incentive to continue to cooperate with third and fourth party payers outside the federal government to add the hospice benefit for non-Medicare patients.

*Service implications*

Approximately seventy percent of all hospice patients are currently of the age or situation that makes them Medicare eligible. Thus, a simple majority of patients and families who want hospice care and for whom it would be appropriate could utilize the service.

Estimating liberally, 105,000 terminally ill persons coast-to-coast would be able to use their Medicare benefits, which they are now using elsewhere. This assumes that

all of these individuals live within the service area of a functioning hospice program of care.

About eighty percent of these patients would then be able to die in their homes, relatively pain free, living out their final days in relative comfort among families and friends.

The families of these patients would receive limited bereavement care . . . therapy designed to prevent illnesses and to mitigate physical and emotional aggravation which can otherwise lead to reliance on the Medicare-covered health system for hospitalizations and physician care.

*Cost implications*

Not one single new person would be added to the Medicare rolls.

No new Medicare entitlement would be created; one hundred percent of the persons affected by the change are already Medicare-entitled and are already receiving Medicare benefits for hospitalization and acute care services.

As a group, the persons affected would account for about half as many inpatient days of care as they would if left within the acute care system. The cost to the Medicare system per inpatient day is most likely to be twenty-five to forty percent less in a hospice inpatient unit than in an acute care hospital.

According to the testimony of the Health Care Financing Administration before this Committee, a terminally ill person now accounts for twenty-one days of hospitalization during the last six months of life. Typically, our studies show that a hospice patient experiences three to eleven days of inpatient hospice care during the last six months of life.

*Implications for the Hospice movement*

Hospice programs of care in America would no longer be at a competitive disadvantage in the health care marketplace in caring for already Medicare-eligible patients.

Terminally ill Medicare eligibles who desire hospice care and for whom such care would be appropriate will no longer to induced, by governmental policy, to seek higher cost, more inappropriate care in the acute care system. Now they will have the choice.

Hospice programs of care will have the remaining incentive to negotiate with employers, unions, insurance companies, and private individuals for services rendered to non-Medicare eligibles.

Hospice programs of care will continue to raise substantial funds privately to retain strong community bases and volunteer support.

*Legal implications*

A separate hospice provider category would be created, thus removing the dangers addressed by Attorney Eisenstat.

Separate provider agreements would create discreet funding streams able to be tracked and accounted for by the Health Care Financing Administration. The potential for fraud, abuse, and the burying of costs of terminal patients elsewhere in the health care system would be substantially reduced.

Hospice programs of care would be accountable for and able to control the quality and delivery of patients admitted for hospice care, instead of having to "broker" the patients out to other providers for reimbursement convenience.

IMPLEMENTATION IS AS IMPORTANT AS LEGISLATION

H.R. 5180 represents a self-standing, comprehensive benefit. We have no recommendations for change and believe the bill should be passed in its current form.

The hospice movement recognizes, however, the potential for misuse of the hospice concept by those whose motivations and methodologies are different from the integrity and carefullness which now characterize hospice practice nationally. We urge that the intent of the Congress be clear that existing and future providers not be able to disguise or simply re-package traditional services and traditional ways of caring for the terminally ill as "hospice" simply in order to qualify for reimbursement opportunities.

We would welcome a partnership between the federal government and the mainstream of the hospice movement in America to develop Medicare conditions of participation that would inhibit such a scenario from developing and provide tough enforcement against offenders. We believe the implementation of H.R. 5180 should be accompanied by joint planning, joint evaluation, and joint review of hospice reimbursement by the Secretary and the National Hospice Organization and National Hospice Education Project.

The need for hospice accreditation is well-recognized by hospice programs. We are pleased that this legislation would permit the Secretary to grant deemed status to an appropriate, qualified accreditation body particularly attuned to hospice.

It is our position that the national Standards of a Hospice Program of Care, as published by the National Hospice Organization, be the foundation for any Medicare conditions of participation and any accreditation mechanism for hospice services. We believe the legislation, as written, is permissive to that end.

CONCLUSION

If I may be permitted a personal note, Mr. Chairman, my own introduction to hospice came originally not from a professional undertaking but from a personal experience. Working within the administration of an outstanding hospital, Bellin Hospital in Green Bay, Wisconsin, I saw what happened to a dear friend, Carl Kouba, who happened to be board chairman of that hospital, when he became terminally ill. I saw that the finest hospital still fell short of meeting the health care needs of its own board chairman—not for lack of skill or wherewithall, but because of the hospital's understandable, otherwise-appropriate curative orientation.

Carl Kouba, more than anyone else, taught me through his own life that there had to be a better way, a more humane way, a more competent way than the way I had known and believed in a member of the hospital administration. Mr. Kouba had had the vision and the courage to inspire Bellin Hospital to create the first hospital-based hospice in America. Then, he became one of its first patients. Through his living and then through his dying, he exemplified the need for hospice as an alternative. The hospice at Bellin Hospital is now named the Carl W. Kouba Hospital in his honor.

Congressman Duncan told this Committee about the experiences of his own family within the past two years. Congressman Panetta told the NHO convention about how his mother was able to fulfill her desire to live out her final days in her own home surrounded by her own family, and how preferable that was to the institutional alternative.

With cancer striking one out of three Americans reaching the age of 74, perhaps each of us can draw into the wellsprings of his own life for the reasons to pass this legislation. But let us pass it not only for reasons of the heart but because H.R. 5180 makes good public policy, good medicine, and good sense.

Mr. RANGEL [presiding]. You are on an accreditation committee, a joint committee, for accreditation of hospices?

Dr. OLSEN. No, sir, I am chairman of a hospice advisory panel to the Joint Commission of Hospital Accreditation.

Mr. RANGEL. What standards are you offering to the Congress to determine what is a hospice?

Dr. OLSEN. Historically, the National Hospice Organization has been aware of the importance of having standards developed throughout the country. In 1978 the National Hospice Organization standards were approved by the membership and the board of directors, and have since been used by many programs, insurance companies and other regulating agencies to establish standards for hospice care.

Mr. RANGEL. OK. You will make a copy of those standards available to the committee?

Dr. OLSEN. They are available for the record, yes, sir.

Mr. RANGEL. Once you get outside of the hospital setting and the home hospices setting, does this organization have freestanding hospice units that have been created just for hospice care?

Dr. OLSEN. There is a model of freestanding hospice care, yes, sir.

Mr. RANGEL. Have they used old hospitals?

Dr. OLSEN. There are many models. There is one instance of a school building being converted. There are other instances of nursing homes, private homes. There are various models.

Mr. RANGEL. But you could not compare the cost of a new hospice to the cost of a new hospital, right?

Dr. OLSEN. I do not have that information available.

Mr. RANGEL. Without having the information, could anyone possibly compare what is necessary for a hospital, with that which I would think is just not necessary for a hospice? Or to put it another way, could you conceive of anything in terms of capital costs that you would need for a hospital—for a hospice, that you would not need for a hospital.

It just seems like a great difference in cost. I do not know.

Dr. OLSEN. Some of the differences are incurred in the types of treatment that are provided or needed.

Mr. RANGEL. What would you need for any type of treatment for a hospice that would be costly, besides a room?

Dr. OLSEN. You need staff and personnel.

Mr. RANGEL. I am talking about capital cost, the structure.

Dr. OLSEN. Structurally the concept is based upon allowing the patient and family to spend their terminal days at home.

Mr. RANGEL. I understand what the problems are in the hospital, I understand what you need in a home—at least that is not my question, whether I understand it or not.

But I am talking about a freestanding hospice. If you had to compare the costs with a hospital and a hospice, would there not be a drastic reduction in the cost of a hospice. Is there any cost for a hospice that I am not thinking about that would be expensive?

Mr. GAETZ. My name is Don Gaetz, Mr. Chairman. I think your point is an excellent one. Hospice inpatient facilities, to the extent to which they are needed as a backup for home care, are much less technologically oriented and cost a lot less to develop, even if one were to build them from the ground up, because of the fact that one does not need CAT scanners and emergency rooms and many of the trappings that normally would be associated with curative care.

Mr. RANGEL. What would you need?

Mr. GAETZ. You would need to have a homelike inpatient environment that is able to accommodate patients and family saying overnight.

Mr. RANGEL. Family staying overnight?

Mr. GAETZ. Occasionally, yes. Families are instructed and educated in how to assist in the care of a family member so when that family member can go home, they are able to be maintained at home without unnecessary trips to the hospital.

So part of what we do is provide some accommodations, sometime so that somebody can actually stay overnight and help and assist in the care of a family member.

Mr. RANGEL. Is this included in the so-called models?

Mr. GAETZ. Yes, Mr. Chairman. There is no model of hospice care on the inpatient side that in any way approaches the cost of developing or building capital construction of a hospital.

Mr. RANGEL. But there is no question in my mind that it could, depending on the degree which you include accommodations for the family.

Mr. GAETZ. If I understand your question, Mr. Chairman, irrespective of the home-like environment that accommodates families

staying overnight occasionally, there is still no comparison between the costs of a hospice, even if one were to build it from the ground up, and the costs of a hospital.

Mr. RANGEL. Thank you.

### STATEMENT OF MWALIMU IMARA, D. MIN., DIRECTOR OF HOSPICE, METHODIST HOSPITAL OF INDIANA

Dr. IMARA. Mr. Chairman, my name is Dr. Mwalimu Imara. I am representing National Hospice Organization and the Indiana Association of Hospices, and the hospices in Indiana and in Indianapolis.

We urge you to pass this bill, Mr. Chairman, and pass it in its present form.

Why?

First, because H.R. 5180, in its present form, captures the best and most reliable experience of the American hospice movement as to the needs of the terminally ill and the methods hospices are using and should use to meet those needs.

Over most of the past decade, the National Hospice Organization has had under way continual interdisciplinary study and evaluation of hospice principles and practices in this country. The formal result of the painstaking effort has been the national standards of hospice care. Upon these standards have been built the private and public hospice benefit plans and State hospice laws in this country. Submitted with our written testimony is a copy of these standards.

A careful examination of the national standards for a hospice program of care will show that H.R. 5180 embodies what hospice care is and what it ought to be at the patient/family level, including such important matters as medical direction, the insistence upon hospice as a home-based service, the functional necessity for hospice to be separately certified, the voluntary component, and the need for the care services to be provided by the hospice interdisciplinary team.

If H.R. 5180 is passed in its present form, it will not be the reimbursement system defining hospice in a restrictive way, but, rather, it will be the needs of the dying and their families defining the reimbursement system in a way consistent with the mainstream of the hospice movement in America.

The second reason why it is this bill that we favor is because H.R. 5180 has the overwhelming support of the people who deliver hospice care throughout this country. The National Hospice Organization, through the near-unanimous vote of its board of directors and in response to the mandate of its membership, is united with the national hospice education project in urging you to pass this bill, in this form, undiluted, and without delay.

Why now? Why pass this bill this year instead of waiting? For three reasons.

First, between today and a year from today, at least 50,000 and perhaps as many as 100,000 Americans for whom hospice may be appropriate will live out their final months. Many will suffer chronic, excruciating pain and other noxious symptoms unsuccessfully controlled in the traditional health care system.

Each of these medicare-eligible Americans will, according to one study, spend 21 of the last 60 days of life in acute care hospitals subjected to batteries of expensive medical-surgical heroics and artificial life support systems, the net result of which will be to neither lengthen life nor improve its quality.

And the final irony, Mr. Chairman, is that what will happen to these Americans will be desired neither by them, their families, nor their attending physicians.

We who work in hospice think and work in getting the most out of days or even hours. Many medicare-eligible Americans will pas many hours and days of terminal illness in the next year.

I hope you will excuse me for saying that these Americans and their families will gain nothing and lose everything if you wait another year.

Second, the hospice movement, itself, will be severely affected by more delay. The National Hospice Organization is painfully aware that many leading American hospices will either close down or fold back if the injustices and inequities in the reimbursement system are not rectified without delay. As those hospices are closing—and they are closing even now—their patients and potential patients are being thrown back into the curative care system—costing medicare money.

Third, there is no reason to delay because the case for support to pass this bill this year is already convincing and persuasive. Years of research and groundwork have gone into this legislation.

There will always be hospice studies under way and there should be. Some were completed last month. Some will be completed next month, some next year, some 3 years from now.

To date, more than 40 public and private, Government and non-Government hospice demonstration studies and cost analyses have been undertaken. Yes, without exception, every single one shows that when hospice is substituted for the already-covered array of medicare services, there is nearly always a net savings and nearly never a net cost.

The current HCFA hospice study is one example of a valuable study which has already given us excellent service definitions—but which started late, did not put the evaluation component in place until a year after the study had already begun, focused out and is not even considering any study of reimbursement methodology, and has already been subjected to many of the same difficulties accompanying similar HCFA studies.

We believe that the HCFA hospice study, assuming it is completed according to the very optimistic schedule heard today, will be concluded just in time to substantially assist the regulatory sector in implementing H.R. 5180. There is no doubt that the HCFA study and those associated with it have been of benefit to this entire effort.

However, passage of the legislation should not be held hostage to the HCFA study.

Mr. Chairman, we recognize that legislative language cannot answer every finite question and every local peculiarity within the hospice movement. In fact, we are extremely pleased that H.R. 5180 gives substantial flexibility to the varying models of hospice care and to the creative evolution of the hospice alternative in

urban and rural settings. We are likewise pleased that the legislation takes strong stands in those areas which describe hospice's uniqueness.

It is in that spirit that we offer you our best efforts not only to pass this bill, but to make it work when it passes. We are reassured that the principal sponsors of this bill are committed to seeing that hospice input, from the grassroots of the hospice movement as well as through the NHO committee structure, will be welcomed in the implementation of H.R. 5180.

You will hear considerable testimony on this bill, both oral and written. I know you will give all of it due weight. However, I urge you to remember that to make a difference, hospice must be different and that the integrity of this concept and the needs of the dying should take a higher priority than the interests of any single provider or provider group.

In hospice, the patient and family become integral parts of the caring team. The actions and decisions of the caregivers are oriented to the needs and convenience of the patient and family. Let that be your criterion today. As you listen to those who will testify, ask yourself: For whom do they really speak?

To decide not to pass this bill would not be a neutral decision. It would be a negative decision perpetuating inequities in reimbursement, discriminating against the hospice alternative, and effectively denying hospice care to many Americans who cannot afford to leave their medicare eligibility behind when they seek health services.

To pass this bill would be to take into account and thoughtfully affirm 8 years of experience in studying and developing the hospice benefit you see before you today in the form of H.R. 5180.

To pass this bill would be to establish and recognize the hospice alternative, while taking us at our word that hospice is, overall, less expensive than the options you are already paying for under medicare. To pass this bill is to hold us to the test of proof that we are what we say we are.

Passing this bill would not add a single new person to the medicare rolls; but would give those who are already eligible an opportunity to choose perhaps a more appropriate, perhaps a more competent, perhaps a less expensive alternative.

There is a hospice chaplain, Rev. Ron Mudd, who is now himself a cancer patient. He frames the essence of this legislation and the essence of what we are doing this way:

> There are times when medical science, despite all its skills and buildings and equipment, simply cannot add more days to people's lives. It is then that hospice can add more life to their days.

Mr. Chairman, I thank you very much. Mr. Gaetz will respond to any questions the Chair has.

Mr. RANGEL. Mr. Duncan.

Mr. DUNCAN. I have no questions, other than to thank you for your fine testimony.

Mr. RANGEL. Do we have a list of the hospice organizations that are represented by the National Hospice Organization?

Mr. GAETZ. Yes, Mr. Chairman, there is a list that can be made available for the record.

Mr. RANGEL. Approximately how many hospices?

Mr. GAETZ. There are 255 provider hospices that are provider members of the National Hospice Organization and at least as many more hospice programs that are in the developmental stage that are not providers at this point.

Mr. RANGEL. Has the American Medical Association taken any position at all in support of hospices?

Mr. GAETZ. Yes, Mr. Chairman. The American Medical Association has affirmatively supported the hospice alternative, and has for a number of years. We have had excellent cooperation from the American Medical Association and its specialty groups over the years for hospice.

Mr. RANGEL. And once a patient has been diagnosed as being terminally ill, there is nothing that the hospice organization would restrict the type of illness—whether it is cancer or anything else. It is just the medical diagnosis, is that correct?

Mr. GAETZ. Yes, Mr. Chairman. And this bill embodies that.

Mr. RANGEL. OK.

With your permission, we would like to request additional questions to be submitted to the organizations by members who are not here, and for that reason the record will remain open and we thank you for your testimony.

It has been very helpful.

Next we will hear from Dr. Gray.

## STATEMENT OF BRADFORD GRAY, PH. D., NATIONAL HOSPICE STUDY ADVISORY COMMITTEE

Mr. GRAY. Thank you.

I am Bradford Gray, Senior Professional Associate at the Institute of Medicine at the National Academy of Sciences. On the agenda it indicates I am a physician. I am a Ph. D.

I am testifying today, however, as a member of an advisory committee for the national evaluation study of hospice care that is being conducted by Brown University, under the direction of Dr. David Greer, the dean of the medical school, with the collaboration of Abt Associates and the Hebrew Rehabilitation Center.

The national hospice study is being conducted with support from the Health Care Financing Administration, the Robert Wood Johnson Foundation, and the John A. Hartford Foundation.

The advisory committee, of which I am a member, meets periodically with the senior study staff to provide advice to the study. The committee is chaired by David Hamburg, M.D., director of the division of health policy research and education at Harvard University.

I have appended to my testimony a list of the advisory committee.

[The list referred to follows:]

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Mr. GRAY. I am here today to give you some information today about the study, its current status, and what it is designed to tell us. Current restrictions on reimbursement for hospice care make it difficult for some hospice programs to carry on. Those that have benefited from the HCFA demonstration in which many reimbursement restrictions have been waived face the end of that waiver period this fall.

In a situation in which committed people have made extraordinary efforts to establish programs to meet the needs they see for the care of terminally ill patients and in which those programs are struggling under restrictions built into current reimbursement systems for medical care, it is understandable why many feel that the legislation before this committee should be considered urgent.

The burden of my testimony today is not to urge that any particular bill be passed or deferred, although I do have some personal questions about the bill itself and some of the premises on which it is based. I want to strongly suggest that the national hospice evaluation study will provide information that will help us avoid problems such as have followed some governmental decisions to pay for certain services.

If legislation on hospice is to be passed, I would urge that it be flexible enough to allow the application of what is learned in the study. We already know that there are enormous variations among hospice programs in the way they are organized, in the services they emphasize, in the intensity and cost of the services they provide.

The danger of considering legislation now is that we will end up favoring one model of hospice care over other models without our knowing which models are in fact most successful in meeting the need of patients and their families, in providing such care at reasonable costs, and in maintaining the spirit that some see as the essence of hospice. Although it is not perfect, the national hospice

study is far more comprehensive and more methodologically adequate than any of the studies that have been done to date.

In 1979, Congress mandated a demonstration and study to determine the implications of reimbursing for hospice services under the medicare program. Thereafter, HCFA accepted applications from a total of 233 hospice programs and selected just 26 hospices for a 2-year experimental demonstration waiver program under which these hospice programs receive reimbursement not otherwise available under medicare regulations.

These hospices, which began receiving reimbursement under the 2-year HCFA waiver in October 1980, are being studied in the national hospice evaluation study. For comparison purposes, the study also includes 14 hospice programs that are not benefiting from the waivers and 10 sites, university medical centers and community hospitals, where patients are receiving conventional care, that is, where no hospice program exists. The design calls for the study of the experiences of more than 3,000 patients and their families in the different types of settings.

An extensive body of information is being collected in the study about each of these sites, about the care that is provided therein, about the effects of that care on patients and their families, and about costs. I might just touch on the major questions the study is designed to answer as a way of suggesting what kinds of information are being collected.

The first major category of questions concerns what services are being provided to the terminally ill in hospice programs. How much do hospices differ in the types and amount of services provided to patients and their families? How does hospice care differ from conventional care?

We are all familiar with the ideas about patient care that have characterized the hospice movement. Clearly, these ideas about the humane care of the terminally ill have great appeal and power. Yet, at this point we know very little about how different programs and settings have translated these ideas into the care of patients and their families.

We know very little about how hospice programs differ from each other in this regard, and we know very little about how the care received by patients in hospice programs differs from care received by similar patients in nonhospice sites, many of which have embraced certain hospice concepts.

So, the first thing the study is intended to document is the types and amount of services that terminally ill patients are receiving, and how this differs among hospice programs.

Second, what is the impact of hospice care on patients and their families? When you examine the amount of pain and discomfort that patients experience, their degree of independence, their psychological status, and their own and their families' satisfaction with the care they receive, are there differences between hospice patients and patients that receive "conventional care?" Are there differences among hospice programs and between the waivered and nonwaivered hospices?

I think we all expect there to be differences. Yet, those are the questions this study is designed to answer.

Third, what is the impact of hospice care on the costs of care? No adequate answer to this question is now available. It is not an easy question to study, because one must include not only the costs incurred in a hospice program but also the total costs incurred by hospice patients. The costs that would have been incurred if the patient were not in a hospice program should also be considered.

The important question about cost that has not been addressed in any satisfactory way I have seen thus far is whether the involvement of patients in hospice programs generally represents a net increase in the amount of services they receive or do hospice services substitute for other more costly services. Most of the projections of cost that I have seen assume that the only care that hospice patients are receiving is in the hospice program.

So, for example, the figures from the three National Cancer Institute sites that are cited in the Warner-Lambert study of $3,500 to $4,500 per patient in the hospice are the costs that are associated with the hospice. Those costs are only a portion of the costs that are incurred in the last 6 months of those hospice patients' lives, which is the cost figure that I have seen the cost of hospice care compared to.

What we need to know is what is the cost of the last 6 months of lives of patients who receive care in both types of settings.

Parenthetically, and this is my own personal view, I am somewhat distressed that the cost premise has been so prominent in the rationale for hospice, in that I think that that is the question about which the most doubt exists at this point.

I think many of us think the ideas here are worthy of support. But for hospice care to be offered as a way that is going to save us some substantial proportion of the costs that are associated with terminal illness, I think at this point has to be questionable, and is, I think, an unfortunate premise for the legislation.

Another one of the questions that is to be answered in the study with regard to cost is what is the effect of the waivers themselves. That is, when you start reimbursing costs and comparing the waivered hospices with the nonwaivered hospices, what is the difference in the costs that are incurred. That will give us some indication of what will happen to costs if the changes in reimbursement system are made.

Similarly, the study is designed to show the effects of the waiver on the hospice programs themselves. Information is being collected in the study to allow comparisons of such factors as the type of staff used, volume and mix of patients, length of stay, extent and use of volunteers, productivity, unit costs of services. Again, making comparisons between the waivered and nonwaivered sites will help us make some estimates of what is likely to happen if there are changes in Federal reimbursement policy.

Finally, the study is designed to shed light on the likely national cost implications of reimbursing for hospice care. This part of the study is based not only on the information that is being collected at the study sites but also on an analysis of costs incurred in the last 6 months of life for a 5 percent sample of all medicare cancer patients and a study of health services utilization and charges for most patients who died from cancer in Rhode Island in 1980 and 1981.

This analysis is designed to help us predict the cost implications of various possible decisions—of changing coverage available under medicare, of covering care in different types of organizational arrangements, hospital-based, home health agency, free standing, and of reimbursing for different types and amounts of service.

Data will be collected in this study until the end of September at the waivered hospices and perhaps for a few additional months in the "conventional care" settings. The final report is due in September 1983, although much of the data analysis will be completed earlier and, with the permission of the sponsors, could be released.

I believe the HCFA people indicated early today they expect the information to be available much in advance of the final report due for the study. The people on the study also agree a lot of data will be much in advance of that final report.

In summation, I would say although the hospice movement has developed and grown with minimal encouragement by the Federal Government, we are now at a point at which a Federal decision about whether and how to reimburse hospice care is of great importance for the appropriateness and quality of care provided to terminally ill patients and for our national costs of health care.

What kind of care for the terminally ill do we wish to encourage? We do not yet have the information from this major evaluation study. We know from past experiences that unanticipated consequences can follow from Federal decisions to reimburse for new types of services or new types of settings. The question now is can we keep and encourage all that is so appealing about the hospice concept while avoiding the mistakes that can follow from the Federal decision to reimburse.

Thank you very much.

[The prepared statement follows:]

STATEMENT OF BRADFORD H. GRAY, PH. D., SENIOR PROFESSIONAL ASSOCIATE, INSTITUTE OF MEDICINE

I am Bradord H. Gray, Senior Professional Associate at the Institute of Medicine, National Academy of Sciences. I am also a regular consultant with the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. I am testifying today, however, as a member of an advisory committee for the national evaluation study of hospice care that is being conducted by Brown University, under the direction of Dr. David Greer, the dean of the medical school, with the collaboration of Abt Associates and the Hebrew Rehabilitation Center. The national hospice study is being conducted with support from the Health Care Financing Administration, the Robert Wood Johnson Foundation, and the John A. Hartford Foundation. The advisory committee of which I am a member meets periodically with the senior study staff to provide advice to the study. The committee is chaired by David Hamburg, M.D., Director of the Division of Health Policy Research and Education at Harvard University.

I want to give you some information today about the study, its current status, and what it is designed to tell us. Current restrictions on reimbursement for hospice care make it difficult for some hospice programs to carry on. Those that have benefited from the HCFA demonstration in which many reimbursement restrictions have been waived face the end of that waiver period this fall. In a situation in which committed people have made extraordinary efforts to establish programs to meet the needs they see for the care of terminally ill patients and in which those programs are struggling under restrictions built into current reimbursement systems for medical care, it is understandable why many feel that the legislation before this committee should be considered urgent.

The burden of my testimony today is not to urge that any particular bill be passed or deferred. I do want to strongly suggest that the national hospice evaluation study will provide information that will help us avoid problems such as have

followed some governmental decisions to pay for certain services. If legislation on hospice is to be passed, I would urge that it be flexible enough to allow the application of what is learned in the study. We already know that there are enormous variations among hospice programs in the way they are organized, in the services they emphasize, in the intensity and cost of the services they provide. The danger of considering legislation now is that we will end up favoring one model of hospice care over other models without our knowing which models are in fact most successful in meeting the need of patients and their families, in providing such care at reasonable costs, and in maintaining the spirit that some see as the essence of hospice. Although it is not perfect, the national hospice study is far more comprehensive and more methodologically adequate than any of the studies that have been done to date.

In 1979, Congress mandated a demonstration and study to determine the implications of reimbursing for hospice services under the Medicare program. Thereafter, HCFA accepted applications from a total of 233 hospitce programs and selected just 26 hospices for a two-year experimental demonstration waiver program under which these hospice programs receive reimbursement not otherwise available under Medicare regulations. These hospices, which began receiving reimbursement under the 2-year HCFA waiver in October 1980, are being studied in the national hospice evaluation study. For comparison purposes, the study also includes 14 hospice programs that are not benefiting from the waivers and 10 sites (university medical centers and community hospitals) where patients are receiving conventional care, that is, where no hospice program exists. The design calls for the study of the experiences of more than 3,000 patients and their families in the different types of settings. (A list of the participating sites is attached.)

An extensive body of information is being collected in the study about each of these sites, about the care that is provided therein, about the effects of that care on patients and their families, and about costs. The information being collected is suggested by the major questions that the study is designed to answer.

1. What services are being provided to the terminally ill in hospice programs? How much do hospices differ in the types and amount of services provided to patients and their families? How does hospice care differ from conventional care? We are all familiar with the ideas about patient care that have characterized the hospice movement. Clearly, these ideas about the humane care of the terminally ill have great appeal and power. Yet, at this point we know very little about how different programs and settings have translated these ideas into the care of patients and their families. We know very little about how hospice programs differ from each other in this regard, and we know very little about how the care received by patients in hospice programs differs from care received by similar patients in non-hospice sites, many of which have embraced certain hospice concepts. So, the first thing the study is intended to document is the types and amount of services that terminally ill patients are receiving, and how this differs among hospice programs.

2. What is the impact of hospice care on patients and their families? When you examine the amount of pain and discomfort that patients experience, their degree of independence, their psychological status, and their own and their families' satisfaction with the care they receive, are their differences between hospice patients and patients that receive "conventional care?" Are their differences among hospice programs and between the waivered and nonwaivered hospices?

3. What is the impact of hospice care on the costs of care? No adequate answer to this question is now available. It is not an easy question to study, because one must include not only the costs incurred in a hospice program but also the total costs incurred by hospice patients and the costs that would have been incurred if the patient were not in a hospice program. Does involvement of patients in hospice programs represent at net increase in the amount of services they receive, or do hospice services substitute for other, more costly services? What happens to the cost of hospice care under the waiver? How do the costs in the demonstration sites differ from the costs in non-demonstration hospice programs? Only when we look at that can we begin to anticipate the effects of changes in reimbursement for hospice care.

4. Similarly, the study is designed to show what the effects of the waiver are on the hospice programs themselves. Information is being collected to allow comparisons of such factors as type of staff used, the volume and mix of patients, lengths of stay, the extent of use of volunteers, productivity, and unit costs of services. This information will allow us to make some better informed judgments about the likely effects of changes in federal reimbursement policy.

5. Finally, the study is designed to shed light on the likely national cost implications of reimbursing for hospice care. This part of the study is based not only on the information that is being collected at the study sites but also on an analysis of costs

incurred in the last six months of life for a five percent sample of all Medicare cancer patients and a study of health services utilization and charges for most patients who died from cancer in Rhode Island in 1980 and 1981. This analysis is designed to help us predict the cost implications of various possible decisions—of changing coverage available under Medicare, of covering care in different types of organizational arrangements (hospital-based, home health agency, free standing), and of reimbursing for different types and amounts of service.

Data will be collected in this study until the end of September at the waivered hospices and perhaps for a few additional months in the "conventional care" settings. The final report is due in September 1983, although much of the data analysis will be completed earlier and, with the permission of the sponsors, could be released.

Although the hospice movement has developed and grown with minimal encouragement by the federal government, we are now at a point at which a federal decision about whether and how to reimburse hospice care is of great importance for the appropriateness and quality of care provided to terminally ill patients and for our national costs of health care. What kind of care for the terminally ill do we wish to encourage? We do not yet have the information from this major evaluation study. We know from past experiences that unanticipated consequences can follow from federal decisions to reimburse for new types of services or new types of settings. The question now is can we keep and encourage all that is so appealing about the hospice concept while avoiding the mistakes that can follow from the federal decision to reimburse.

HOSPICE DEMONSTRATION SITES

*East*

Cabrini Hospice, New York, New York.
Connecticut Hospice, Inc., Branford, Connecticut.
Genesee Region Home Care Association, Rochester, New York.
Hospice of North Virginia, Arlington, Virginia.
Hospice of the Good Shepherd, Inc., Waban, Massachusetts.
Medical College of Virginia, Richmond, Virginia.
Overlook Hospital, Summit, New Jersey.
University of Massachusetts Medical Center, Worcester, Massachusetts.
Burlington VNA, Burlington, Vermont.

*Midwest*

Bellin Memorial Hospital, Green Bay, Wisconsin.
Bethesda Lutheran Medical Center, St. Paul, Minnesota.
Hospice Care, Inc., Seminole, Florida.
Hospice, Inc., Miami, Florida.
Lutheran Medical Center, St. Louis, Missouri.
Rogers Memorial Hospital, Oconomowoc, Wisconsin.
St. Benedict Hospital and Nursing Home, San Antonio, Texas.
VNA of Dallas, Dallas, Texas.

*West*

Boulder County Hospice, Inc., Boulder, Colorado.
Community Home Health Care of Seattle, Seattle, Washington.
Hospice of Marin, San Rafael, California.
Hospital Home Health Care Agency of Albuquerque, Albuquerque, New Mexico.
Hospital Home Health Care Agency of California, Torrance, California.
Providence Medical Center, Portland, Oregon.
San Diego Hospice Corporation, San Diego, California.
San Pedro Peninsula Hospital, San Pedro, California.
Santa Barbara VNA, Santa Barbara, California.

HOSPICE NONDEMONSTRATION SITES

*East*

Fall River Hospice, Fall River, Massachusetts.
Faulkner Hospital Hospice, Boston, Massachusetts.
The Visiting Nurse and Home Care Services of Greater Hartford, Inc., Hartford, Connecticut.
Old Colony Hospice, Stoughton, Massachusetts.
Hospice Care of Rhode Island, Rumford, Rhode Island.
St. Peter's Hospice, Albany, New York.

Pondville Hospice Collaborative, Norfolk, Massachusetts.

*Midwest*

Abbott Northwestern Hospice, Minneapolis, Minnesota.
Metropolitan Medical Center, Minneapolis, Minnesota.
North Memorial Center, Minneapolis, Minnesota.
St. John's Hospice, St. Paul, Minnesota.

*West*

Hospice of Pasadena, Pasadena, California.
Los Angeles VNA, Los Angeles, California.
Granada Hills Community Hospital—Hospice, Granada Hills, California.

CONVENTIONAL CARE SITES

*East*

Boston City Hospital, Boston, Massachusetts.
Charlton Memorial Hospital, Fall River, Massachusetts.
Roger Williams General Hospital, Providence, Rhode Island.
St. Anne's Hospital, Fall River, Massachusetts.
The Memorial Hospital, Pawtucket, Rhode Island.

*Midwest*

Marshfield Clinic, Marshfield, Wisconsin.
United Hospitals, St. Paul, Minnesota.

*West*

Memorial Hospital Medical Center of Long Beach, Long Beach, California.
Santa Monica Medical Center, Santa Monica, California.
St. John's Hospital and Health Center, Santa Monica, California.

Mr. RANGEL. Mr. Duncan.

Mr. DUNCAN. Thank you, Mr. Chairman. I would like to ask, what type of models are you considering in your study, and particularly, do they vary according to reimbursement methods, or do they vary according to services provided? I wonder if you would elaborate on that.

Mr. GRAY. Appended to my testimony is a list of the study sites that are included in the study. The waivered hospices themselves are all being reimbursed, as I understand it, under the same approach—a cost-based approach.

The major difference among the models being studied is whether they are hospital based, based in a home health agency, freestanding hospices, of which I think there are three among the waivered hospices.

They have tried to match these types with nonwaivered hospices. I have not gone through in detail to see how successful that was. They have tried to reach comparability.

Mr. DUNCAN. Thank you. Thank you, Mr. Chairman.

Mr. RANGEL. Your position, Dr. Gray, is the same as the administration's; is that right?

Mr. GRAY. My position is that if this is being premised on hospice providing a great cost saving, I do not think the answer to that question is available at this point.

Mr. RANGEL. Let me try again. The administration believes we should not legislate until after their demonstration project is completed. You are advising them on the demonstration project.

So you concur or advise them—you are advising us not to legislate.

Mr. GRAY. Well, I think that I can only say at this point I am speaking for myself. And I have not fully analyzed the bill that is before you.

The argument that I would want to make is whatever legislation is passed should be flexible enough that it will allow what we learn from this study to be applied in the administration of the reimbursement system.

Mr. RANGEL. We do not have the study.

Mr. GRAY. What?

Mr. RANGEL. We do not have the study, do we?

Mr. GRAY. We do not have the study.

Mr. RANGEL. So we cannot legislate until we have the study, you are testifying, I think.

Mr. GRAY. I am testifying that if you are legislating on the basis that there is going to be a great cost saving by passing this legislation, you do not have the answer to that question yet. If you are convinced that the ideas that are associated with hospice and what people are trying to do merits removal of the reimbursement restrictions, then it seems to me that you have a basis to proceed.

If the legislation is sufficiently nonrestrictive, that would allow the application of what is learned in the study in the development of the regulations, then I think that the passage of legislation and the continuation of the study at the same time is compatible.

Mr. RANGEL. I see. I assume the other panelists would believe that your responses to the administration would apply to Dr. Gray's testimony.

Dr. IMARA. I will let Mr. Gaetz respond for me.

Mr. GAETZ. Mr. Chairman, the only additional statement I think is worthy of making is that 95 percent of what Dr. Gray related to us as the potential results in data of the demonstration projects will be extremely helpful I would think to the Secretary in implementing this legislation. But what I think we have to clarify is that the HCFA demonstration project is not studying or addressing any alternative reimbursement techniques or methodologies, which seems to be a central issue.

And second, the project is not measuring in a usefully scientific way the substitution effect of hospice for curative care which is the essence of this legislation.

I think that there are 40 studies that have been completed to date. Perhaps they do not measure up in some people's views to what the HCFA study measures up to. This is not a critique of the HCFA study, but rather an indication that it has been the middle 1970's that we started getting a commitment from the administration to do the study.

We are going to be in the middle 1980's before we get the results. The results will be useful in implementing the bill. But the results will not impact and will not study reimbursement methodology. I think that is a decision for the Congress.

Mr. RANGEL. Mr. Duncan.

Mr. DUNCAN. I have no further questions.

Mr. RANGEL. I thank the panel on behalf of the full committee. The record will remain open for additional questions.

The next panel includes the Gray Panthers, Frances Klafter, cochair, National Health Task Force; Crandall D. Graves, Jr. and

Tracy Z. Graves from Springfield, Va., and John Ward from Gaithersburg, Md.

## STATEMENT OF FRANCES KLAFTER, COCHAIR, NATIONAL HEALTH TASK FORCE, GRAY PANTHERS

Ms. KLAFTER. Mr. Chairman, members of the subcommittee, I certainly appreciate the opportunity to be here today. Of course I am sure you are aware that we are an unrelated panel. I have no idea what the other members of the panel will say. So I can speak only for my organization.

I have submitted for the record a very brief statement which I assume will be included in the record. I want now to make just a very brief general statement.

When we received the notice of these hearings, our immediate reaction, the reaction of our committee was of course we are in favor of hospice, anything that broadens the hospice movement. I think the Gray Panthers and the hospice movement are about the same age, and from the beginning Gray Panthers have been very supportive of the hospice movement. We have a number of members on boards over the country, and many who are volunteers. Therefore our inclination is to talk in terms of whether this is in the interest of medicare beneficiaries, whether it is the humane thing, for a humane society to do.

We are well aware that is not the only consideration, in this particular year, certainly, and that there is no use for us to talk only in those terms. So we proceeded to study the fiscal implications. We are certainly not in a position to do research studies ourselves, but we do not come and make statements before a congressional committee without making every attempt to inform ourselves.

Our committee was very impressed with the studies, the Warner Lambert study, and other studies that were cited in material that we received and had on file on the hospice movement.

Certainly we are not prepared to give expert testimony, such as one would expect from the Health Care Financing Administration. But my impression from what I heard here today, and I hope the impression of the members of this committee, is that if we wait for an absolute final word from HCFA as to whether or not this legislation is cost effective, there will be many, many people dying without the humane, warm, meaningful services of the hospice movement.

I was very impressed with the testimony of Congressman Panetta, that showed that the authors of this bill had done a great deal of research.

We would urge this committee to do all it can to hasten the passage of this legislation. And we are so happy to be here to say that—to offer our voice in favor of it.

[The prepared statement follows:]

STATEMENT OF FRANCES KLAFTER, CO-CHAIR, NATIONAL HEALTH TASK FORCE, GRAY PANTHERS

It is indeed a pleasure to appear before a Congressional Committee to applaud pending legislation, an experience that has been somewhat rare for us of late.

The Gray Panthers have been strong supporters of the hospice movement since its inception—or ours, I'm not sure which came first. Many of our members serve on hospice boards or as volunteers for hospice groups.

The hospice movement has not only shown us the way to bring comfort to the terminally ill and to ease the pain of their final days, but has given solace and strength to family members and shown them how to be a warm and close part of the team assisting the dying.

The Gray Panthers are not prepared to give testimony based on our own research as to the fiscal impact of reimbursement for hospice care under Part A of Medicare. We are, however, familiar with the findings of the study commissioned by the Warner-Lambert Foundation on this subject. We are convinced, on the basis of the findings reported there that the cost of furnishing hospice care, as outlined in this proposed legislation, would be less than the present costs of providing services to the terminally ill, often in expensive, and sometimes frightening, institutional surroundings.

We urge this Committee to approve this amendment to Medicare legislation, and to do all that it can to hasten its passage, and thus not only to help to bring a more appropriate form of care to the terminally ill, but at the same time to cut Medicare costs for services to this group of patients.

I thank you for this opportunity to appear before you today to add our voices to those urging approval of this legislation.

Mr. RANGEL. The statement of Mr. Graves.

## STATEMENT OF CRANDALL D. GRAVES, JR., AND TRACY Z. GRAVES, SPRINGFIELD, VA.

Mr. GRAVES. Thank you, Mr. Chairman. My name is Crandall Graves. With me is my wife, Tracy Graves. I submit our testimony for the record. But I would like to take a few minutes to highlight in a personal way the reasons we support the legislation before you.

My mother was first diagnosed as having breast cancer in March 1977. She had a radical mastectomy to remove the tumor. However, the cancer continued to spread and involved first her lungs and then her brain. She was in and out of hospitals and underwent chemotherapy and radiation treatment.

During that time her courage and will to live remained strong, and each time she returned to her work. In May 1980, just 7 months before her death, she was present when Tracy and I were married in Lynchburg, Va. In September 1980, she was admitted to Fairfax Hospital. Though the hospital tried to treat her, it was clear that my mother was not going to get better.

She was unhappy in the hospital, and wanted very badly to go home. That was when Tracy and I were first introduced to the hospice concept. At first Tracy and I were apprehensive about the hospice home care program. We were both working full time, and I was attending graduate school part time.

We faced the option of leaving her in the hospital which would have provided the proper medical care but would not have given her the constant attention we felt she deserved, or we also had the choice of bringing her home with us and placing her under the care of hospice.

Tracy and I sat down with my mother and together decided that home care under hospice would be the best thing for my mother and for us.

Hospice policy is to make the patient as comfortable as possible during his or her remaining days. In my mother's case, drugs were prescribed to control the pain while still permitting her to function as normally as possible.

But my mother, Tracy, and I soon learned that in addition to the excellent medical care provided by the hospice doctors and nurses,

equally valuable support services were provided by the hospice personnel and volunteers.

Dealing with the death of a family member is not easy. As the inevitable progressed and my mother realized she was getting weaker every day, she lowered her defenses and tried to be as happy as possible while she was still alive. To the day of her death, on December 9, 1980, she never lost hope that she would live, but with the help of hospice she accepted what was happening to her body and mind.

At a time when she had every reason to be depressed and withdrawn from the world, she remained cheerful and seemed to enjoy life as she was able to live it. I attribute her bright attitude to the help and sympathetic treatment she received from hospice.

I truly do not feel she would have been able to deal with her illness and the prospect of her death the way she did if she had been in the hospital.

I want to reemphasize that if we had not had hospice care to help Tracy and me, there would have been no alternative but to leave my mother in the hospital. There she would have received care, expensive care, but it would not have been the kind of care which she and Tracy, and I received from hospice.

Not only did the Hospice of Northern Virginia provide a tremendous service to my mother. They also provided an invaluable service to Tracy and me. As we look back on the time my mother spent with us, we consider it to be the most meaningful and rewarding period of our lives. However, as we were going through it sometimes it was very difficult for us.

At times my mother became frustrated when she realized that her mind and body could no longer perform the tasks they once could, and she would vent her anger on Tracy and me. At times we were scared, and the hospice people were there 24 hours a day, every day, to help us through our crisis.

The least important consideration to Tracy and me at the time was the cost of my mother's care. We wanted to make my mother as happy and as comfortable as possible, and decided we would worry about the bills at a later date. As it turns out, the cost of the hospice home care program was considerably less expensive per day than the cost of a hospital stay.

The costs of hospice home care was approximately $67 per day. The hospice costs included all doctor and nurse care, the services of a professional social worker, medical supplies, a home health aid 8 hours a day while Tracy and I were at work, a trained volunteer who supported us in many ways, and around the clock nursing care during my mother's final days.

My mother was too young to qualify for medicare which is the subject of this legislation. Yet, I think there is an important lesson here in terms of costs of terminally ill patients who are covered by medicare. We wholeheartedly support H.R. 5180. Although my mother was not eligible for medicare we feel that the hospice care benefits all of society and it certainly should be provided for under the medicare program.

Hospice provides services that a hospital cannot provide, and at less cost.

In closing, it is clear that without hospice, my mother could not have spent the last few months with us. Instead she would have been forced to spend the last part of her life in a hospital away from those who loved her. The hospice concept of care for the terminally ill may not be an option that all people would choose, but it should be available to those who can and want to care for their loved ones in their homes.

Our experience shows that making hospice care available under medicare and private insurance programs could significantly lower the overall cost of health care.

Again, we thank you, Mr. Chairman, for the opportunity to testify before this subcommittee in support of H.R. 5180.

[The prepared statement follows:]

STATEMENT OF CRANDALL D. GRAVES, JR., AND TRACY Z. GRAVES, SPRINGFIELD, VA.

Mr. Chairman and Members of the Committee, thank you for the opportunity to testify before the Subcommittee in support of H.R. 5180, legislation which will provide for the coverage of Hospice care through the Medicare program. We represent no organization but feel that our personal experience with Hospice of Northern Virginia, which cared for my mother, Betty Lee Graves, during her illness and death, will provide evidence of the positive benefits which are realized under the Hospice program.

In March of 1977, my mother was diagnosed as having a malignant tumor of the left breast. A radical mastectomy was performed to remove the tumor, and after several weeks in the hospital and several months of recovery, it appeared that she had been cured. She returned to her full time job and resumed normal activities. Then in January, 1979, doctors discovered that the cancer had spread to her lungs. The prognosis for long-term recovery was considered slim by the doctors; however, with chemotherapy and her strong will, the cancer went into remission, a development her doctors said was remarkable. Several months later she again returned to work. But a year later, in February, 1980, it was discovered that the cancer has spread to her brain. After radiation treatment, the cancer seemed to disappear and my mother again demonstrated her remarkable recovery capabilities. In May of that year, seven months before her death, she was present when Tracy and I were married in Lynchburg, Virginia. But my mother's health was declining rapidly.

In September, 1980, she was admitted to Fairfax Hospital. Though the hospital tried to treat her, it was clear that my mother was not going to get better. While she retained her mental capacities, she was very weak physically. She was unhappy in the hospital and wanted very badly to go home.

That was when Tracy and I were introduced by the hospital social worker and by a friend who is a Hospice volunteer to the hospice concept. At first Tracy and I were apprehensive about the Hospice home care program. We were both working full time and I was attending graduate school. However, after seeing how my mother suffered from depression in the hospital, Tracy and I consulted her doctors who agreed with our opinion that she had reached the point where curative treatment was no longer effective.

We faced the option of leaving her in the hospital, which would have provided the proper medical care but would not have given her the constant attention we felt she deserved, or of bringing her home with us and placing her under the care of Hospice. Tracy and I sat down with my mother and together decided that home care under Hospice would be the best thing for my mother and for us.

Hospice policy is to make the patient as comfortable as possible during his or her remaining days. In my mother's case, drugs were prescribed to control the pain while still permitting her to function as normally as possible. But my mother, Tracy, and I soon learned that in addition to the excellent medical care provided by the Hospice doctors and nurses, were equally valuable support services provided by Hospice personnel and volunteers.

Dealing with the death of a family member is not easy. The Hospice staff comfort and support not only the patient but the family as well. My mother was very strong willed and had a great fear of death, as most of us do. Tracy and I had great difficulty dealing with her fear.

The professional staff and volunteers always answered all of our questions and comforted us. We met on several occasions with members of the Hospice staff to dis-

cuss our problems, and because of their thorough training, they were able to provide us with the help we desperately needed. With a great deal of skill they encouraged my mother to talk freely about her feelings.

As the inevitable progressed and my mother realized that she was getting weaker every day, she lowered her defenses and tried to be as happy as possible during her remaining days. To the day of her death on December 9, 1980, she never lost her hope that she would live; but with the help of Hospice, she accepted what was happening to her body and mind. At a time when she had every reason to be depressed and withdrawn from the world, she remained cheerful and seemed to enjoy life as she was able to live it. I attribute her bright attitude to the help and sympathetic treatment she received from Hospice. I truly do not feel that she would have been able to deal with her illness and the prospect of death the way she did if she had been in the hospital.

The medical care provided by Hospice of Northern Virginia, in our opinion, was thoroughly professional. My mother was visited at least once or twice weekly by Hospice nurses and every two weeks by Hospice doctors. Both doctors and nurses came to our home whenever Tracy and I felt that she needed medical attention. The Hospice medical staff was supplemented by a social worker, home health aides, and a trained volunteer. Over the course of the two months that she spent with us, the Hospice staff received many late hour calls for help; and they always responded immediately.

I want to reemphasize that if we had not had Hospice care to help Tracy and me, there would have been no alternative but to leave my mother in the hospital. There she would have received care—expensive care—but it would not have been the kind of care which she—and Tracy and I—received from Hospice.

The high-quality care that was provided by Hospice did not end with the death of my mother. Hospice continues to provide care to the family after the patient's death. After my mother died, Tracy and I felt a tremendous void in our lives. Hospice volunteers continue to stay in touch with us and help us with our loss. And we know that we always have someone to talk to if the need arises.

In sum, not only did Hospice of Northern Virginia provide a tremendous service to my mother, they also provided an invaluable service to Tracy and me. As we look back on that time my mother spent with us, we consider it to be the most meaningful and rewarding period of our lives. However as we were going through it, some times were very difficult for us. At times my mother became frustrated when she realized that her mind and body could no longer perform the tasks they once could, and she would vent her anger on Tracy and me. At times we were scared, and the Hospice people were there 24 hours a day, every day, to help us through our crisis.

The least important consideration to Tracy and me at the time was the cost of my mother's care. We wanted to make my mother as happy and comfortable as possible, and decided we would worry about the bills at a later date. As it turned out, the cost of the Hospice home care program was considerably less expensive per day than the cost of a hospital stay. The cost of Hospice home care was approximately $67 per day. The Hospice cost included all doctor and nurse care, the services of a professional social worker, medical supplies, a home health aide eight hours a day while Tracy and I were at work, a trained volunteer who offered support in many ways, and around-the-clock nursing care during my mother's final days.

Although the cost of Hospice care was far less than that of the hospital, ironically for us the out-of-pocket cost was greater for Hospice than for the hospital. Her insurance covered the full cost of her hospital treatment, but would pay only for licensed professional care under Hospice; as a result, Tracy and I paid the cost of the home health aide—amounting to $51 of the $67 per day for Hospice care.

While there was a significant difference in the cost of care at the hospital versus that provided by Hospice, the difference in quality of care should also be emphasized. In the hospital, my mother had access to the best medical care available, but at that stage very little could be done to improve her condition. The individualized care she received from Hospice at home simply was not possible in the hospital. Doctors and nurses at a hospital just cannot sit for hours on end comforting the patient, nor are there trained social workers and volunteers to counsel the families. In short, at a hospital you are paying excessive amounts for intensive care the patient does not need; with Hospice, for less money, you get the exact care the patient and family need.

My mother was too young to qualify for Medicare—which is the subject of this legislation. Yet I think there is an important lesson here in terms of cost for terminally ill patients who are covered by Medicare. We wholeheartedly support H.R. 5180. Although my mother was not eligible for Medicare, we feel that the hospice

care benefits all of society—and certainly it should be provided under the Medicare program. Hospice provides services that a hospital cannot provide, and at less cost.

In closing, it is clear that without Hospice my mother could not have spent the last two months with us. Instead she would have been forced to spend the last part of her life in the hospital away from those who loved her. The Hospice concept of care for the terminally ill may not be an option that all people would choose, but it should be available to those who can and want to care for their loved ones in their homes. Our experience shows that making hospice care available under Medicare and private insurance programs could significantly lower the overall cost of health care.

Again, we thank you for the opportunity to testify before this subcommittee in support of H.R. 5180.

Mr. RANGEL. Thank you for your courageous and helpful testimony.

Tell me, when your mother left Fairfax Hospital, did she come straight to your home?

Mr. GRAVES. Yes, sir.

Mr. RANGEL. So the hospice that you refer of northern Virginia provided that hospice in the patient's home as opposed to another building.

Mr. GRAVES. Yes, sir. The hospice provided nurses and doctors when they were needed.

Mr. RANGEL. Thank you.

Mr. Ward.

## STATEMENT OF JOHN WARD, GAITHERSBURG, MD.

Mr. WARD. Good morning, Mr. Chairman.

My name is John Ward. I am from Gaithersburg, Md. Thank you for the opportunity to add my support to the proposed legislation.

I would also like to briefly discuss the meaning of hospice care from a personal view.

My wife died from cancer in February. During the last 2 months of her illness we were cared for in our home by the Montgomery Hospice Society, Montgomery County, Md., which was our joint decision. And I say we were cared for, because they also paid close attention to me and my family. Because of the hospice, this really permitted my wife and I to share one of the most intimate, tender, and loving periods of our life together, rather than the desperate nightmare that terminal illness can become.

To us, it meant she could spend this time in familiar surroundings, not among strangers in an institutional setting. I could participate directly in managing and providing her care, not just stand helplessly by. And it gave us assurance that everything possible was being done that could be done for her comfort 24 hours a day.

This was really very important.

Also very important, I could keep the household running at the same time, without the burden of the endless trips and hours that were required when she was in the hospital.

This was really only possible because of the hospice. They provided what I think are three key ingredients. First, an experienced coordinator that could anticipate my wife's needs, run interference with her physicians, locate and coordinate obtaining the supplies, equipment and drugs required, and provide the support I needed to take on this responsibility of keeping her at home.

The second vital element was the support of trained, sensitive volunteers, provided by the hospice. They become part of the family. This enabled me to lose minimum time from work, and not worry that my wife was in good hands.

The third and most important factor was the hospice concept itself, which enabled the care elements to be applied in a manner that realistically conformed to my wife's needs.

One case, of course, is not maybe that perhaps significant, but just for your information, the total cost of these 2 months of often extensive care, excluding the drugs, which would be needed in any case, was $1,200—2 months. This allowed me to cope with the major bills that were left over from all of the time we spent in treating her illness.

So I would urge support of my reasonable legislation that would promote the financial viability of hospice care organizations. My family and friends who became aware of hospice through our case also enthusiastically encourage the increased availability of hospice care.

Thank you.

Mr. RANGEL. Mr. Duncan.

Mr. DUNCAN. I have no questions.

Mr. RANGEL. This testimony has been very helpful. It is courageous to come forward and discuss it. But I want you to know whatever reservations you have, that it is helpful for the record and helpful for us individually. Thank you very much.

Next, Congressman Courter from New Jersey.

Mr. Gradison has put your full statement in the record earlier this morning. We welcome you here.

## STATEMENT OF HON. JIM COURTER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. COURTER. Thank you, Mr. Rangel, and Mr. Duncan. It is a pleasure to be here.

I appreciate your taking a few minutes of your precious time in allowing me to testify before the committee.

I have always had a particular interest in this ever since I was elected to Congress, because one of the very first hospice care treatment centers was started in New Jersey about 7 years ago at Riverside Hospital. It has been a thriving institution since that time.

I understand that during the past 7 years there has been hospice care treatment centers established in virtually every State of the United States. I do not think I can impress upon you the importance of this bill more than other witnesses have. I know both you two gentlemen are intensely aware of the situation and extremely interested in the concept.

I visited several hospice treatment centers in New Jersey, and find them to be, for a number of reasons, an appropriate method of care with regard to the terminally ill. I heard it once said that instead of adding days to someone's life, hospice care adds life to someone's remaining days, and it truly does that.

It seems to me that this type of concept is one that is overdue in the country. It adds a great deal of dignity and warmth and human

compassion to the individual who is terminally ill. I also think it is an appropriate and compassionate way to work with the family.

Family members have a very difficult time under these circumstances, as we are all aware. I think this is one of the unique legislative initiatives that is not only extremely compassionate and heart warming, but, when properly performed, can save the Federal Government dollars.

As you two gentlemen, Mr. Duncan and Mr. Rangel, are well aware, hospice treatment care costs about one-fifth of what true hospitalization does. All I can urge upon this subcommittee is to listen to the witnesses and examine the legislative alternatives. It is my sincere hope and prayer that the Congress can act properly and quickly on this measure during the next number of weeks and certainly the next number of months.

I want to thank you very much, gentlemen. My full remarks I hope will be in the record.

Mr. RANGEL. Without objection.

[The prepared statement follows:]

STATEMENT OF HON. JIM COURTER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. Chairman, thank you for the opportunity to deliver testimony in support of H.R. 5180, the Hospice Care Reimbursement Act, which would make hospice care reimbursable under the Medicare program. This issue is of great importance to individuals in every state of our country, and is of particular importance to my constituents in New Jersey as one of the first hospice programs in the United States opened in Boonton Township, New Jersey less than eight years ago. The concept of hospice care has continued to incease in popularity since that time, and there are now hospices in every state in our nation.

The medical prognosis of terminal illness is a reality that many individuals and their families and friends are forced to accept and endure. Terminally ill patients are confronted with the difficult task of acknowledging and adjusting to their impending death. This situation obviously places a tremendous emotional and financial burden on these individuals and their loved ones.

The hospice concept is an approach dedicated to helping the terminally ill be providing the services necessary to allow terminally ill patients to live out the rest of their lives in dignity and peace in the familiar and comfortable environment of their home. I am strongly in support of hospice care because it provides a compassionate alternative for individuals who choose it, after determination has been made by the individual and his physician that further curative measures will neither lengthen life nor improve its quality. I once heard it said that "instead of adding days to someone's life, the hospice movement adds life to an individual's days." A visit to any hospice center would certainly confirm this.

Despite the tremendous public and physician support of hospice care as an effective substitute, our country's health care reimbursement system does not acknowledge hospice care as an acceptable alternative to hospital care. The current reimbursement system, for Medicare and many private insurers, does not include the hospice benefit in their hospital insurance coverage. The federal government now spends nearly one and a half billion dollars for terminal care each year. The average cost of hospice treatment is equal to one fifth that of hospital care. Yet terminally ill persons are penalized through a loss of health benefits if they choose the less costly, and perhaps more effective, alternative of hospice care.

Mr. Chairman, I urge the Committee's support for H.R. 5180, so that the the thousands of those who die in America every year will be able to do so in a way which minimizes the pain and suffering of the dying person and his loved ones while simultaneously making more efficient use of federal health care dollars. The concept of hospice care is an alternative to hospital care at a fraction of the cost.

Mr. DUNCAN. I have no particular questions, other than to thank you for an excellent statement. We read it earlier. I know of your

interest in this particular subject. I know you can be a great deal of help to us all down the line.

Mr. RANGEL. I join with my friend in our appreciation.

The next panel—Cabrini Medical Center, John Reilly, executive vice president; Ohio Hospice Organization, Kim DeVore, president; Hospice of Cincinnati, Barry Brooks, vice president of finance; the Hospice of the Monterey Peninsula, Jerome L. Rubin, medical director; and Illinois State Hospice Organization, Sue Fremgen, director at large, St. Thomas Hospice, Darien, Ill.

**STATEMENT OF JOHN REILLY, EXECUTIVE VICE PRESIDENT, CABRINI MEDICAL CENTER, AS PRESENTED BY HAROLD LEFKOWITZ, SENIOR VICE PRESIDENT FOR FINANCE**

Mr. LEFKOWITZ. Mr. Chairman, my name is Harold Lefkowitz. I am the senior vice president of the Cabrini Medical Center. Mr. John Reilly, our executive vice president, was unable to testify due to the weather. He was delayed in New York. Like health care, the weather is unpredictable.

Mr. RANGEL. What is the weather in New York?

Mr. LEFKOWITZ. There was so much fog, I could not see.

I will attempt to summarize that which Mr. Reilly's written testimony—which was given to the committee.

Mr. RANGEL. The full statement of Mr. Reilly will be placed in the record without objection.

Mr. LEFKOWITZ. I would also like to comment on some of Mr. Reilly's remarks, and also what I heard today.

Cabrini Medical Center is a 493 bed medical center in New York with an affiliated nursing home, clinic, and a hospice unit. Our hospice is one of the 26 Federal demonstration projects as well as 15 New York State demonstration projects.

We are a free-standing hospice and therefore we are very, very much committed to hospice care.

We applaud the subcommittee's efforts and we think that H.R. 5180 is a good start towards creating a permanent place for hospice in the health care system. We do, however, have several concerns with the bill.

You have heard testimony here today about the cost of hospice care. I think in order to look at hospice care properly, we must put costs in its proper perspective.

Let's first evaluate hospice care, let's first evaluate the program, and then let's look at the costs. I think we tend to look at costs first, and what the program is all about second.

You have heard references as to how costly it is or how cheap hospice care is. You have heard testimony that perhaps this would be new costs to the system. I suggest perhaps that medicare already pays for a lot of hospice care, and does not know it or want to acknowledge it.

You have heard testimony here today that there are between 600 and 800 hospices in the country. I suggest that that number is slightly incorrect. There are over 7,000 types of hospices in the country. Every hospital in this country provides some form of hospice care. Terminally ill patients are in every single hospital in this country. Is that where they should be?

That is one of the questions we have to ask.

Is the alternative of hospice care better for the patient—then let's look at the cost.

My background, Mr. Chairman, is in accounting and finance. And I know costs as well as or better than anyone. I can study costs as well as or better than anyone. You have heard your administration say that we are now studying the 26 demonstration programs, we now must evaluate the costs, we now must evaluate the data.

I suggest to you, in front of me today is some of the cost reports that we have to submit in our hospice program. We submit a quarterly cost report in the most minute and detailed fashion.

We submit detailed bills on every one of our patients. I suggest that the data to evaluate is there.

Let's look at it now and not wait.

I also suggest the cost records of your 7,000 hospitals in relation to all terminally ill patients that are there. We have the data to evaluate. Let's not delay.

In looking at the bill, I think there are certain things that have to be addressed and looked at. While we are totally in support of the concept of the bill, we are concerned about certain of the inflexible ceilings and criteria in the bill.

We are concerned placing a cap on three bereavement visits, about placing a cap on 20 percent of the patient's stay being inpatient.

We can accept 20 percent of 180 days, we can't accept 20 days of the actual stay. We also suggest you rethink some of the bureaucratic regulations that found their way into the bill. Particularly the paperwork regarding volunteers.

Do you expect us to ask our volunteers to punch timeclocks?

I recognize that time is short and I just would like to close with two points. One, the bill suggests a 2-year reimbursement system. No logical hospice or hospital can go into any program when we don't know what is going to happen after 2 years.

Second, I would like to invite everyone on the committee and anyone else interested to please come and see our hospice.

[The prepared statement follows:]

STATEMENT OF JOHN M. REILLY, EXECUTIVE VICE PRESIDENT, CABRINI MEDICAL CENTER

INTRODUCTION

Mr. Chairman and other distinguished members of the Subcommittee on Health, my name is John M. Reilly, and I am Executive Vice President of Cabrini Medical Center, located in New York City. I am accompanied today by Sister Josephine Tsuei, of the Missionary Sisters of the Sacred Heart, Harold J. Lefkowitz, Senior Vice President for Finance of Cabrini Medical Center, and by David H. Eisenstat, counsel to Cabrini Medical Center. Cabrini is vitally concerned with the needs of the terminally ill, and is gratified that the Subcommittee is holding this hearing on H.R. 5180, a bill designed to provide for Medicare coverage of hospice care services. We greatly appreciate this opportunity to address this issue.

Mr. Chairman, H.R. 5180 is a good start at dealing with the task of providing hospice care services to those in need. We at Cabrini are concerned, however, that certain provisions in the Bill may discourage hospitals from instituting hospice programs, and may actually not be cost-effective. Our major concerns by far relate to the Bill's reimbursement provisions, but before I go on to our specific comments, I would like to tell you a little about Cabrini and our commitment to hospice care.

DESCRIPTION OF CABRINI MEDICAL CENTER

Cabrini Medical Center is a 478-bed full service acute care hospital located on East 19th Street in lower Manhattan. Cabrini operates a "free-standing" 15-bed hospice and home care program located a few blocks from the Hospital, and is affiliated with a 200-bed extended care facility in Dobbs Ferry, New York. Additionally, the Medical Center has an affiliation with the Stuyvesant Polyclinic, a community based out-patient facility located near the Hospital. Cabrini has long been a leader in developing innovative health care programs in our primary service area, which includes the Bowery, Chinatown, Little Italy, the Lower East Side, and parts of Brooklyn. In this regard, we have been involved in such undertakings as a hospice program, an alocholism treatment program, paramedic training, sign language instruction, and CPR programs, to name just a few.

Cabrini is sponsored by the Missionary Sisters of the Sacred Heart, a world-wide religious order whose special mission includes the rendering of care to those in need without regard to race, creed, color or financial status. Cabrini also serves a large number of poor and elderly beneficiaries of the Medicaid and Medicare programs.

CABRINI'S HOSPICE PROJECT

Since October, 1980, Cabrini has operated a hospice demonstration project—one of 26 federal and 15 state demonstration projects. Cabrini's hospice includes a home care program, and a 15-bed in-patient facility located several blocks from the Hospital.

In 1981, Cabrini's hospice program cared for 91 participants. The average length of stay in the program was 43 days. On the average, each participant received 13 days of in-patient care—consisting, on the average, of 1.3 in-patient sessions of about 9 to 10 days duration. In total, 30 percent of the patient days in Cabrini's program were in-patient days. The average cost per participant was $13,000.

With the current demonstration project scheduled to be completed in March, 1983, Cabrini is particularly interested in permanent legislation which would recognize hospice care as a separate level of care, distinct from other types of covered health care under the Medicare program. Based upon our experience, we are convinced that there is a compelling need for hospice care, the full extent of which cannot truly be measured until coverage is extended by all third-party payors. Cabrini is committed to providing for that need, and we applaud the Subcommittee's effort in this regard.

COMMENTS REGARDING H.R. 5180

Mr. Chairman, let me begin my comments on the bill by noting that its greatest virtue is that, for the first time, hospice care would be recognized as a district level of care requiring Medicare coverage. This treatment is long overdue. Traditionally, "Hospice type" care to terminally ill patients has been furnished in settings that are geared to curing the sick—a philosophy of treatment that is fundamentally different from the hospice's palliative care approach. Caring for the terminally ill in curative settings has been needlessly costly. It has all too often, for example, led to the use of expensive therapies and surgical procedures in instances where an individual's main needs were comfort and dignity. Thus, we whole-heartedly support the Subcommittee's efforts to encourage this cost effective and humane substitute. We cannot, however, support certain provisions of H.R. 5180 which we feel will be counterproductive to your efforts.

*The cap on reimbursement*

Our greatest concern with the proposed legislation is in the area of reimbursement. While Cabrini and its sponsors are fundamentally committed to the concept of hospice care, the institution's resources are finite, and therefore, we must approach this legislation from a practical viewpoint.

The cap on reimbursement contained in Section 3 of the Bill may significantly reduce our financial ability to provide hospice care. As currently written, Section 3 would create a first year reimbursement cap for New York City hospices of approximately $7,000 per individual program participant. As our actual operating statistics for 1981 indicate, this projected cap amount would have been woefully inadequate to cover our hospice care costs provided to date under the demonstration program. As noted above, Cabrini's 15-bed, free-standing, in-patient facility and home care program handled 91 participants in 1981 at a total cost of $1,194,000—roughly $13,000 per patient. Thus, the Bill would have left us with a $6,000 reimbursement shortfall for each program participant.

Even if Cabrini's hospice program were hospital-based, rather than free-standing, a serious reimbursement problem would still exist under the Bill. Indeed, during 1982 we plan to move Cabrini's hospice program from the free-standing facility into the hospital building as a cost containment measure. Specifically, we anticipate that this move will reduce our total program cost to $1,079,000, and our cost per participant to $10,000—a $3,000 savings per participant. Obviously, the cost limit imposed by the Bill would still dramatically under-reimburse our program.

As our situation shows, it may be impossible for health care providers to reduce hospice costs to within the reimbursement cap as presently written. A part of the problem is that hospital or nursing home-based hospices will still be, for medicare cost-finding purposes, just another department of the health care facility. As such, the hospice will be saddled with a portion of the high administrative and general costs involved in curative care. This will result from the use of "stepdown cost allocation"—a fundamental accounting methodology that providers in the Medicare program are required to use. Under this method, a portion of the administrative and general costs involved in curative care are allocated to various departments or "cost centers" within the health care institution, including the hospice. While a hospital would be required to allocate part of these costs to its hospice, it would then be reimbursed for these costs only up to the hospice cap. While the use of a free-standing hospice will avoid this particular cost allocation problem, the heavy capital costs associated with the free-standing hospice will in many cases be prohibitive. At bottom, the projected cost ceilings of H.R. 5180 may operate to eliminate, rather than encourage the growth and development of hospice care.

Finally, we are also concerned with the Bill's provision for a possible prospective reimbursement system of an undefined nature to be developed in 2 or 3 years. Institutions seeking to enter the hospice field will be faced with considerable uncertainty and risk due to the unclear nature of the prospective reimbursement system. Both current and potential providers of hospice care may be unwilling to assume the risks created by the Bill. Here again, the legislation may actually discourage the provision of hospice care, rather than expand it.

*Regulatory problems*

In addition to our reimbursement concerns, we are troubled by what appear to be certain regulatory problems built into the Bill. On the other hand, the Bill is in some places too rigid in its requirements; on the other hand, it sometimes grants the Secretary of Health and Human Services too much discretion to establish guidelines. One example of the former is the Bill's three bereavement visit limitation. While our experience indicates that three visists are generally quite adequate, we have encountered situations where more than three visists are required. We suggest that the Bill be revised to provide for an average of three bereavement visits per participant.

Similarly, the Bill contains inflexible limitations on coverage. Restricting coverage of individuals to two 180-day periods may, in some instances, lead to severe hardships. While our average length of participation has been 43 days, two of our patients have been in the hospice program for more than a year. Two "erroneous" diagnoses out of 91 participants is really quite a good record. The course of nature cannot always be accurately predicted, and the hospice provider should not be penalized for an occasional deviation from the norm.

The Bill's limitation of coverage for in-patient days to 20 percent of the actual days a participant is in a hospice program also seems too restrictive. Our experience has been that participants spend 30 percent of their time as in-patients (out of a 43-day average length of stay). We suggest that either the percentage in the Bill be raised, or, preferably, the 20-percent limitation be applied to the total days available per election period—that is, 20 percent of 180 days.

The Bill's grant of overly broad discretion to the Secretary is exemplified by the provision in Section 4 that directs the Secretary to define "crisis period" for purposes of 24-hour crisis period coverage. The unfettered latitude granted to the Secretary may result in unnecessary restrictions. The need for such coverage should be determined on a patient-by-patient basis, rather than according to some wooden definition established without reference to the needs of particular patients.

*Miscellaneous comments*

There are two other noteworthy points about H.R. 5180. First, the Bill does not provide for hospice coverage under the Medicaid program. Without such coverage, many terminally ill, indigent persons may simply go unserved by hospice programs—a tragic eventuality.

Second, the Subcommittee should be aware of the staggering bureaucratic paperwork load now faced by providers under the Medicare program. The Bill would seem to proliferate this paperwork burden to everyone's disadvantage.

As one example, the record-keeping requirements for the use of volunteers appears rather burdensome. Hospices would be required to maintain records on the cost savings and service expansion achieved through the use of volunteers. To put it bluntly, it is just not practical to ask volunteers to punch a time clock. While the Bill anticipates that the cost of hospice care will be lowered through the maximum utilization of volunteers, the cost of the required record-keeping may well defeat this purpose.

*Conclusion*

While the Bill is certainly a step in the right direction, it has several important shortcomings. Cabrini hopes that its comments will be helpful to the Subcommittee in evaluating H.R. 5180. We would be pleased to respond to any questions the Subcommittee may have, and would welcome an inspection of our hospice program and a tour of our facility.

Mr. RANGEL. Ms. DeVore.

## STATEMENT OF KIM DeVORE, PRESIDENT, OHIO HOSPICE ORGANIZATION

Ms. DEVORE. Mr. Chairman, members of the committee, my name is Kim DeVore, I am president of the Ohio Hospice Organization. Though I have been acting 5 years in the development and delivery of hospice services in Ohio, I am here today in an unsalaried volunteer capacity.

No part of my personal income comes from hospice and I won't make or lose any money if this bill passes or fails.

The 24 hospices of Ohio have sent me here. I reflect, also, the stated position of the Southwest Ohio Academy of Family Practitioners, which are 400 physicians practicing in Greater Cincinnati.

Irrespective of any differences in philosophy or function, the overwhelming mainstream of the hospice movement in Ohio supports H.R. 5180, we support it fully and on their behalf, I urge you to pass it without delay.

I have submitted for the record detailed written testimony outlining some of the history and frankly some of the problems we have faced in Ohio and specifically in Cincinnati, because of the current institutionally intensive reimbursement system for terminal care.

Allow me to summarize the position of the mainstream of the hospice movement in Ohio with specific reference to three essential issues:

One, cost effectiveness; two, fraud and abuse; three, separate provider status for hospice.

Our experience in Ohio leads to the conclusion that cost control is directly related to assuring the home-based nature of hospice. This is the real cost cap in this bill.

The section of this bill which describes appropriate utilization as being 80 percent home care and 20 percent inpatient care is not a legislative restriction on the delivery of hospice care, but it is an affirmation of the hospice practice and performance in Ohio and the Midwest.

Yes; it takes hard work and creativity and doing things very differently in order for a dying person to be able to live out their life at home, surrounded by their family instead of in the institution.

The Ohio hospice movement is achieving the 80-20 ratio today because it is right and it is good hospice. If the integral section of the legislation is watered down for the self-interest of people who want to get into the hospice business, then the Congress will have made it profitable to not take measures to allow the dying to live at home.

We believe inpatient care must be a part of the hospice benefit, although a subordinate part.

We support H.R. 5180 because it provides for the home care and inpatient components.

However, we believe hospice inpatient care is different from and costs less than hospital inpatient care. Our written testimony evidences that conclusion.

The Ohio Hospice Organization has little interest in passing a bill that will make it financially more attractive to keep dying people in hospitals, even if those hospitals have the word "hospice" painted on the sign outside.

The primary danger of fraud and abuse in hospice is the temptation to use hospice as a medical marketing device, merely an attractively packaged rearrangement of existing services.

Even though the inadequacies of the existing services give rise to the need for the hospice alternative in the first place, the simplest form of such abuse is for the hospice to be essentially a broker of other people's existing services, rather than an actual provider itself to be a simple entity that doesn't really provide the inpatient home and bereavement services integral to the care of the terminally ill.

If such a brokerage is permitted, hospice becomes, at best, an add-on coordinated agency and at worse, a false doorway through which dying persons pass searching for an alternative, but finding only a passageway back to the traditional care givers, their traditional cost, and their traditional services.

One protection against such a scenario is to pass this bill undiluted, because this bill, as written, places responsibility for providing core services squarely on the hospice itself.

Another protection which we solicit is in the implementation of this legislation and the writing of conditions of participation that State hospice organizations, those of us who have dealt with licensure and quality control issues that are closest to the potential problems feel this should be included in this by the HHS program and that that be the intent of this Congress.

We strongly support this legislation in its insistence that licensure be left to the State and that the law be a condition of participation and reimbursement.

Inherent to hospice is the concept in practice of integrated total care throughout the home care and inpatient components.

The heart and soul of this legislation is its recognition that hospice care is and should be separately identified, separately funded, and separately held accountable for what is finally a unique form of care.

This will divert millions into hospice programs from medicare. As a practical matter, unless there is a separate provider arrangement to account for the dollars, there is a real risk that the true cost of hospice care could be disguised; that overhead expenses

could be artificially moved around in ways unintended by and unrelated to this bill; and that finally, the search for accountability would turn into a confused maze.

It would be inefficient and undesirable to trace funds for a single patient through, first, the hospice, then a home health care agency and then a hospital.

Yet, if each of these could have a provider agreement allowing them to provide partial care service to a hospice patient and be reimbursed for partial care, then this fragmentation would occur.

I don't want to have to come back here 5 years from now to apologize to this Congress for being one of the people who urged you to pass the hospice benefit that was perverted. That apology may be necessary unless clear and unambiguous accountability be provided in a single, responsible hospice provider.

The notion that a separate provider agreement is somehow a duplicatve, erroneous burden on providers is a false argument. If there isn't a hospice provider agreement for a hospice program, then the funds to pay for one patient could flow through two or three provider agreements such as one for hospital, one for the home health agency, and one for someone else providing some other component of care.

Instead of one set of records and one funding stream and one set of books, providers would be filling out and medicare would have to track two or three sets.

This fragmentation already plagues the long-term care system and has led to such congressionally directed initiatives as the channeling experiments designed to lessen the problem of fragmentation.

People concerned with creating unnecessary bureaucracy or paperwork should favor hospice having an integral single-provider agreement, as opposed to further fragmentation and duplication.

In short, we believe the workability and integrity of the benefit require separate provider agreements for hospice.

Mr. Chairman, for 8 years we have been evolving and maturing the hospice benefit, which is before you today in the form of H.R. 5180. This is a total program of care.

The whole is greater in impact than the sum of its parts. It deserves to be passed in its integrity and entirely and we urge you to do it this year.

Thank you, Mr. Chairman.

[The prepared statement follows:]

STATEMENT OF KIM DEVORE, PRESIDENT, OHIO HOSPICE ORGANIZATION

CREDENTIALS

Mr. Chairman, Members of the Committee, ladies and gentlemen, my name is Kim DeVore. I co-founded and am currently President of the Ohio Hospice Organization, a member of the Board of Directors for Hospice of the Miami Valley, Incorporated. In addition, I was elected in 1978 to serve as a member of the first Board of Directors of the National Hospice Organization. During my three year tenure as a Volunteer, I held the position of Secretary in 1979–80 and Treasurer in 1980–81.

I left Hospice of Cincinnati as a salaried employee in early 1980, and am not a paid employee of any hospice program in the country. I am a member of the Volunteers for Hospice of Cincinnati, the Ohio Hospice Organization, a member of the National Hospice Organization and a community administrator who cares about having Hospice available as an alternative program of caring for the dying. I am

now a small business owner concerned about the high cost of Health Care Benefits for my employees. I do not believe health care costs should continue to escalate up when alternative health care programs can be made available to the public.

DEFINITION OF HOSPICE

The following is a definition of Hospice as entered into the record of the United States Congress, House of Representatives, Committee on Interstate and Foreign Commerce, Subcommittee on Health and the Environment. A Discursive Dictionary of Health Care, February, 1976, 94th Congress, 2nd Session:

Hospice: a program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency such as a visiting nurse association. Originally a medieval name for a way station for pilgrims and travelers where they could be replenished, refreshed, and cared for; used here for an organized program of care for people going through life's last station. The whole family is considered the unit of care and care extends through the mourning process. Emphasis is placed on sympton control and preparation for and support before and after death, full scope health services being provided by an organized inter-disciplinary team available on a twenty-four-hours-a-day, seven-days-a-week basis. Hospices originated in England (where there are about 25) and are now appearing in the United States.

HISTORY-HOSPICE OF CINCINNATI, INC.

On January 6, 1977, six community leaders met in Cincinnati, Ohio to discuss the feasibility of starting a Hospice in our community. Two physicians, a priest, a registered nurse, a student nurse and myself as a health care business specialist represented a cross section of professional community minded individuals who began a dialogue of; what is Hospice? Could it work in our community? What and how should we implement this new concept? Is it practical? At the conclusion of this meeting, projects were assigned, research began and future meeting dates were arranged.

By May, our third meeting was scheduled. Research conclusions of each individual were presented to twenty-five (25) leaders representing eighteen (18) community organizations. The decision of this broad based community group was that further exploration of the concept of Hospice was needed, but additional questions evolved, i.e. Was anyone else in the community providing this type of care? If not, could currently available resources such as Visiting Nurse Service or Public Health be utilized? Was there a need? Did we have patients in the community who needed this specialized type of care? The American Cancer Society had already published data that indicated that Cincinnati had an unusually high rate of cancer. Did this mean that Hospice care was needed?

On June 1, 1977, I was hired as Project Feasibility Co-ordinator via a two (2) month grant from the Christ Hospital Oncology fund. Research consisted of contacting every Health Care Agency, Community Chest, surrounding hospitals, and the Cincinnati Board of Health to secure information as to services provided, in comparison to services needed and how these compared to the Hospice program.

DETERMINING A NEED

A study of the medical records at Christ Hospital revealed there were a sufficient number of patients with the prognosis of death being predictable and eminent on their last admission. Most of these patients didn't require hospitalization, however, since there was no other resource available they were hospitalized. A cost impact study was completed and it showed that a definite cost savings would be realized if these patients could have been cared for at home. With the results of one study at Christ Hospital and the knowledge of the number of hospitals in the Greater Cincinnati area, it was determined that a number of patients needed the services of a hospice program. Our community agency survey showed that no Home Health Services were available from 5:00 p.m. each day until 8:30 or 9:00 a.m. the next day. Holiday and weekend coverage was non-existent. Therefore, when a patient needed help from 5:00 p.m. to 9:00 a.m. usually they were taken by ambulance to a local hospital emergency room. In most cases they were admitted and usually died in the institution.

During the time these results were compiled, community meetings continued and on August 1, 1977 Hospice of Cincinnati was Incorporated as a non-profit organization. Approximately eighty (80) community leaders volunteered to serve on the first

Board of Directors. Approximately thirty (30) of this group were nominated and accepted to serve.

During the following eighteen (18) months, research, evaluation, fund raising, hiring of staff and securing additional community support were pursued. It became very clear to us that many Home Health Care Agencies and hospitals definitely cared for the terminally ill. Both physicians and nurses were surveyed and said, "Yes, I care for the dying". However, no formal interdisciplinary team or continuity of care between home and in-patient existed or were being planned.

### WHAT IS HOSPICE?

As our small staff and Board soon learned Hospice was not a place. It was not a hospital having a pallative care unit or beds available. Hospice is a philosophical concept of care which defines specific goals and objectives. It suggests a methodology and continuity of care including home and in-patient care with special emphasis being placed on Home Care. Hospice defines an interdisciplinary team consisting of physicians, nurses, clergy, social workers, volunteers, patient and family.

Hospice assists patients to live until they die. It does not assist patients to die. Hospices uses few medical technologies, so there is no question of "pulling the plug". Rather, it is "letting nature take it's course" while maintaining comfort.

### ADOPTION OF STANDARDS

At the National Hospice Organizations Second Annual Meeting and Sixth National Hospice Symposium, hosted by Hospice of Cincinnati, Standards for a Hospice Program were set forth and adopted unanimously at the November, 1979 meeting.

### DELIVERY OF HOME CARE

"On December 1, 1979, Cincinnati began the home care program by accepting our first patient. It was projected that we would service fifty-six (56) patient/family units during 1979. During the first year, one hundred seventy nine (179) patient/family units were served. One hundred-two (102) physicians had referred patients to the program. Volunteers provided three thousand (3,000) hours of service visiting their assigned patient/family.

Sixty-five (65%) percent of the patients were able to die peacefully in their homes, surrounded by their families and friends, which was their wish." [1]

### INPATIENT PROGRAM DEVELOPMENT

Plans for an in-patient facility evolved simultaneously. We have eight (8) hospitals within an approximate one mile service area. Each hospital was contacted and supported plans for an in-patient unit. Community leaders, hospital administrators and physicians were surveyed to determine a location. It was agreed that the best plan would be to have a unit free of any one hospital. This would eliminate the need for physicians having to obtain admitting privileges and hopefully encourage admittance of patients to an independent institution that was not in competition with the other hospitals.

Bethesda Hospital came forth and offered the former Deaconess Home, on their grounds, but not as a part of the hospital. This seemed an excellent idea. It would provide several benefits such as radiation therapy, palliative care but not acute care and other services such as laboratory testing, X-ray, speech therapy, occupation therapy, etc. In addition these services could be provided on an as-needed basis by contracting on a fee for service basis. This allowed for the best of two worlds at the least cost: hospital care resources without admission at the higher room charges.

Hospice of Cincinnati proceeded to secure approval from CORVA our local health systems planning agency. Our plan was to provide Hospice Care at a cost of $95.00 per day while the average cost of area hospital rooms was $185.00 a day. This was a significant cost savings to all involved.

Support for this plan was overwhelming and after a rather lengthy review process approval was granted in November, 1978. Implementation of the plan was a major step. Contractual arrangements were negotiated and signed with Bethesda and Hospice. Architects were selected and fund raising began. $750,000.00 had to be raised and in seven (7) months the community came forth and funded the renovation cost of restoring the former dormitory residence of the Deaconnesses. Thirty-Five (35)

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[1] Hospice of Cincinnati, Inc., Update. No publication date.

corporations, twenty-five (25) foundations and many other individuals contributed to meet the fund raising goals.[2]

This was to be the Hospice in-patient facility and house the Administration and Home Care Team. Upon meeting with the Deaconnesses, who has given up their residence, they stated that their original community service goal was to care for the terminally ill. Hospice was so totally in line with their goals that they also donated to the development of the in-patient facility.

### HOME HEALTH CARE AGENCY CERTIFICATION

Home Health Care in Ohio is certified by the State Department of Health and approval was obtained by Hospice of Cincinnati, Inc. in 1980. Fee for services were now able to be billed under the traditional insurance reimbursement system. However, we discovered that limits on who could go into the home, (nurses, social workers, home health aides, etc.) the number of visit limitations, and the length of time on a visit were soon to cause financial setbacks.

The traditional Home Health visit by a registered nurse might consist of 15 to 30 minutes. Hospice visits could last anywhere from 30 minutes to several hours. The additional time was not billable as some of the time was involved with family member needs, such as, education on caring for the physical needs of the patients, counseling, etc. Since only the patient was classified for services that could be reimbursed; all family care, education and/or counseling was ignored and could not be reimbursed. In Hospice, family care is just as important as patient care.

As we began the delivery of care we soon found that some of the regulations regarding delivery of care and the other services provided were too restrictive and not in the best interests of Hospice patients and their family. Such limitations became apparent when the first visit made must be a nurse even if another professional might be more appropriate. In cases where a patient is in a hospital and discharged to home as the appropriate level of care, we found that families panicked and were not always able to cope. Many of these patients were often transferred to a Nursing Home at a higher cost per day before Hospice care was available. In planning for a patient to come back to their own home, a social worker visit was essential to provide counseling and reassuring the family to plan for the arrival of the patient. Since the patient was not in the home, a registered nurse was not deemed necessary.

### VOLUNTEERS

Volunteers play a very important role in Hospice. They augment service and provide a spirit which would be virtually impossible to achieve in any other way. This use of voluntarism should be continued and would be by H.R. 5180.

### FINANCIAL DIFFICULTIES

During 1981 after the opening of the in-patients facility, Cincinnati found itself in a difficult situation. While trying to realize the National Hospice Organizations Standards of Hospice Care and to reach the goal of not turning any one away because of a lack of ability to pay, financial doom was eminent.

### IN-PATIENT LICENSURE

The in-patient unit was classified, under a Ohio law, as a Speciality Hospital-Hospice. Medicare regulations do not recognize the classification of Speciality Hospital-Hospice. The unit could not be classified as a hospital because Ohio law states that an emergency room must be provided. Hospice does not have need of an Emergency Room. This is one example of the rules that were not appropriate to Hospice. Therefore, a Speciality Hospital-Hospice section of the law became a logical step. After several trips to Washington and numerous meetings with HCFA representatives reimbursement under Medicare was refused.

### HOSPITAL ASSISTANCE

In this difficult situation Bethesda Hospital stepped forward and offered to take over the program and include it as a part of the hospital until December, 1982. It was stated that if Hospice of Cincinnati could become financially viable again, then Bethesda would return it to the community. The Community Volunteer Board of

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[2] Hospice of Cincinnati, Inc., Update. No publication date.

Directors has now dissolved, and a few remain as Volunteer Advisory Board Members.

Reimbursement for Hospice as a total program and concept of care would have prevented the loss of this community program. The affiliation and operation of the program by one hospital limits the community physicians as they will not pursue admitting privileges with yet another hospital. What prevents the specially trained Hospice Nursing Team from being pulled to another part of the hospital because of a nursing shortage? Hospice staffing ratio of registered nurses per patient is significantly higher in Hospice than in a traditional hospital floor staffing pattern. These are only a few of the pitfalls and potential hazards for dilution of the Hospice Program.

"The terminally ill patient usually has two major areas of concern besides their physical complaints of pain, nausea, diarrhea, etc. The first area is that they will become quietly isolated, that communications will decrease, and that they will be left alone. Isolation will occur too by being placed at the end of a hall with no one willing to maintain openness and support. The second fear possibility is that the patient will be subjected to painful, often uncomfortable procedures that might prolong life, but not a desirable quality of life.

These fears of abandonment in one form or another we hope will not be a part of the Hospice concept, but a thing of the past. The quality of life should be preserved at all cost in terms of dollars and cents and human compassion. The Hospice concept demands the utmost respect for the patient with the patient maintaining their own complete identity." [3]

I am providing this synopsis to show you how one community supported a Hospice program in hopes that a methodology of reimbursement would be available for this most wanted and needed program.

### HOSPICE PROGRAMS IN OHIO

In Ohio, I represent 14 cities in our state, from large populations to rural communities. We have 10 additional community Hospices in development and planning stages to deliver care within two years or less. Other groups have been identified that would like to start a Hospice in their area and are in the process of organizing their communities to implement Hospice.

Hospice of Dayton began in September, 1978. Almost a year later certification for Home Health Care was granted. This program was formed with support of eight community hospitals. Today, the hospitals provide financial support, staffing and in-kind service.

To-date, sixty (60%) percent of the patients served have died at home. Seven hundred sixty-five (765) patients have been served. Of these, three hundred eighteen (318) died at home with one hundred and eighty eight (188) dying in a hospital and twenty-four (24) dying at a nursing home. The average in-patient hospital stay was three (3) days. The total number of days in the program per patient averages sixty-six (66) days. The average cost per patient day in the home care portion of the program is ten dollars and twenty-two cents ($10.22).

Hospice programs exist in most parts of the United States, and many more are being planned. Efforts to develop and sustain programs financially and philosophically have come from contributions of individuals from all walks of life, both professional and non-professional. Fund raising for the largest portion of Hospice operating funds can not continue forever. Hospice care versus acute care in the hospital in-patient setting has been proven cost effective.

### SUPPORT H.R. 5180

Gentlemen, I ask you to affirm the standards of Hospice care as established by the National Hospice Organization which have been embraced in H.R. 5180. H.R. 5180 is the only bill being considered for Congressional approval at this time that will protect the integrity of the Hospice movement. Hospice care will flourish best in an intact organization formed around the hospice concept, whose focus is not on prolonging life but on a low cost way to make the last days of a person about to die, as comfortable as possible. This will assure that the care delivered is in the best interest of the patient and family. And preservation of the hospice concept intact will assure the cost-effectiveness of H.R. 5180.

Our present enemy is the reimbursement system. The fault lies here in Washington with a Medicare Reimbursement System that simply does not recognize or pro-

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[3] Hospice of Cincinnati, Inc., written communication. No publication date.

vide an incentive, in other words, a separate reimbursement category for Hospice. What is the incentive for people back home to start a Hospice after seeing what has happened in Cincinnati? Why does the government, as a matter of public policy create incentives to provide the highest cost? Why is there no incentive for those of us who want to provide support? No one has ever indicted Hospice for not providing quality care.

Without the passage of H.R. 5180, Hospice of Cincinnati's story could multiply and nationally all Hospice programs could be forced to close or never be started. On behalf of the five thousand (5,000) volunteers in Ohio, all of the concerned citizens, volunteers, professionals and staff of Hospice programs both in Ohio and Nationally, I urge you to support H.R. 5180.

We urge you, if you are interested in both cost containment and better care for those about to die, please support H.R. 5180. Thank you.

Mr. RANGEL. Mr. Brooks from Cincinnati.

**STATEMENT OF BARRY D. BROOKS, VICE PRESIDENT AND FINANCIAL MANAGER, BETHESDA HOSPITAL & DEACONESS ASSOCIATION, CINCINNATI, OHIO**

Mr. BROOKS. Mr. Chairman, I am Barry D. Brooks, vice president and financial manager, Bethesda Hospital & Deaconess Association, Cincinnati, Ohio.

I am pleased to have this opportunity to present our views on H.R. 5180, a proposal to provide coverage of hospice care under the medicare proposal.

I would like to give you a brief history of Bethesda Hospital's involvement in Hospice of Cincinnati, Inc., who I represent today. I am a former board member of the Hospice of Cincinnati.

Founded in 1977, Hospice of Cincinnati, Inc. initially contracted with a home care agency to provide home care and coordinated all services through a medical director, lay and clergy volunteers.

In December 1979, Hospice became a home health provider and began to offer home health care through their own employees.

To date, over 1,000 patients and families have been cared for through the home care program. During this initial phase, Hospice also began to plan for their own inpatient facility.

A facility was located, a certificate of need for an 18-bed inpatient unit was obtained, and a successful fund drive was conducted which resulted in more than $1,500,000 being donated for renovation and startup expense.

The 18-bed inpatient unit was approved as a special hospital under the Ohio CON law and was opened in April 1981.

An application was then filed for medicare certification. In October 1981, after much discussion and negotiation, HCFA notified Hospice of Cincinnati that the application for medicare certification, as provided in the medicaid law.

We were told, "Congress would have to act before we can pay for hospice."

In December 1981, Hospice of Cincinnati, its funds exhausted, asked Bethesda Hospital to assume the financial and operating responsibilities for the future of the program.

Hospice of Cincinnati failed as a freestanding community resource because it could not meet the medicare definition of a hospital.

Bethesda Hospital, to date, is not receiving reimbursement to date for these patients in its freestanding facility.

Mr. Chairman, hospice is a concept whose time has come. Legislative action by Congress is necessary and desirable.

Our view on H.R. 5810 is that it goes beyond what is necessary for the following reasons:

First, its design requires a hospice to be "all things to all people" once they have made the hospice election. The hospice will have to take over and pay for functions now performed by families, cancer associations, churches, and other community groups because "medicare now pays for it."

Simple examples are first, 24-hour continuous care in a "crisis situation," and second, a hospital bed at home, now often provided free by cancer associations, would be provided by hospice if prescribed by the physician.

Those who formerly provided this service free would put their resources in areas not covered by medicare.

Second, but maybe most important, I believe H.R. 5180 would add significantly to the administrative cost of the health care system by adding hospice as a separate division of service in addition to existing hospital, skilled nursing, and home care divisions.

This would affect HCFA, each State, joint commission, and each provider. A whole new set of consultants and experts will be born.

The draft of joint commission standards for hospice is the first example. It is some 80 pages long.

Third, the cap, which is included in the bill, is not a true cap. I am told that the cap includes all the cost of services covered by medicare during the last 6 months of life for all patients who died of cancer.

It includes chemotherapy, radiation therapy, surgery, and other attempts to prolong or save lives.

It does not include respite care, home care during a crisis, custodial care, and bereavement visits.

The cap is acknowledged as an apples-and-oranges comparison, thus 75 percent of the current cost was established as a limit.

This does not provide any real control as patients will elect into the program at various times before death. They could have all of the costly life-prolonging services and then elect into hospice.

If this really is not a cap, then there is nothing to insure that the hospice cost will not gravitate toward the cap as there is no real incentive to operate in a cost-effective manner.

I believe that this could result in a net increase in cost rather than a net savings.

Fourth, if the cap is truly a cap, then hospice cannot survive. The bill requires each hospice to become an insurance company, an HMO for the terminally ill. Yet there is no incentive for assuming the risk as the hospice is reimbursed at "cost or the cap, whichever is less."

Fifth, the requirement of the "hospice election" will prevent many patients from seeking hospice care simply because of their fear, founded or unfounded, of what they do not understand.

Sixth, the bill legislates coverage for new services not now covered, including:

(a) 24-hour home care in a "crisis situation." This could be more costly than inpatient care as the staffing ratio is 1:1, as compared

to approximately three patients to one nurse in inpatient units and, thus, is not an efficient use of resources.

(b) Respite care in an inpatient unit. There probably is need to cover a few days for relief for the family. I believe the Secretary should include a limited number of days—such as a maximum of 5 days—of such care for a terminally ill patient as a "covered service," just as the Secretary does for other services. And I say, for example, the Catscanner.

Mr. RANGEL. I have to interrupt. Your statement is lengthy, so if you could conclude, it would be helpful so the other witnesses will have a chance to be heard before we conclude.

Mr. BROOKS. We feel that a more appropriate solution is to modify the medicare definition of a hospital under section 1861(e)(1) of the law, to include the definition of a hospice.

Thus, a definition would read:

> The term hospital means an institution which: (1) is primarily engaged in providing, by or under the supervision of physicians, to inpatients (a) diagnostic services and therapeutic services for medical diagnosis, treatment and care of injured, disabled, or sick persons, or (b) rehabilitative services for the rehabilitation of injured, disabled or sick persons, or (c) palliative and supportive services, including respite care which provide physical, psychological, social and spiritual care for terminally ill persons.

The existing definition of a home care agency already includes hospice home care.

Because hospice care would then fall under existing hospital and home care definitions, and existing codes and regulations such as life safety codes and utilization review, new regulations, unthought of or duplicative regulations, would not be necessary.

Also, cost-effectiveness measures such as section 223 limits for routine care and home care visits are already in place.

This alternative would let hospitals, who so choose, establish home health care agencies and deliver coordinated hospice care. It would allow home health agencies to make arrangements with hospitals and/or skilled nursing facilities to provide the inpatient part of a coordinated hospice program they would develop.

It would allow independent groups such as Hospice of Cincinnati, Inc., to establish independent hospices as a community resource, provided they could do so cost effectively.

This alternative essentially provides everything that H.R. 5180 does, except:

First, bereavement visits; second, custodial care, and third, homemaker services.

I believe these services could all, or selectively, be added by the Secretary as covered services under existing regulations. The Secretary would then have the flexibility to determine the cost effectiveness and desirability of including each of the above and without requiring congressional action.

I personally believe the cost of some of these are more appropriately borne by the family, hospice volunteer, or through local fundraising efforts.

As I said earlier, I personally do not believe we should attempt to pay for custodial care with Federal Government dollars.

Thank you for this opportunity. I want to close by reminding you of two earlier statements. First, HCFA's statement to us that "Congress will have to act before we can pay for hospice."

Second, "Hospice is a concept whose time has come."

[The prepared statement follows:]

STATEMENT OF BARRY D. BROOKS, VICE PRESIDENT AND CHIEF FINANCIAL OFFICER, BETHESDA HOSPITAL AND DEACONESS ASSOCIATION, REPRESENTING HOSPICE OF CINCINNATI, INC., CINCINNATI, OHIO

Mr. Chairman, I am Barry D. Brooks, Vice President and Financial Manager, Bethesda Hospital and Deaconess Association, Cincinnati, Ohio. I am pleased to have this opportunity to present our views on H.R. 5180, a proposal to provide coverage of hospice care under the Medicare program.

BACKGROUND

I would like to give you a brief history of Bethesda Hospital's involvement in Hospice of Cincinnati, Inc., who I represent today. Founded in 1977, Hospice of Cincinnatic, Inc. initially contracted with a home care agency to provide home care and coordinated all services through a Medical Director, lay and clergy volunteers. In December, 1979, Hospice became a home health provider and began to offer home health care through their own employees. The date, over 1,000 patients and families have been cared for through the home care program. During this initial phase, Hospice also began to plan for their own inpatient facility. A facility was located, a Certificate-of-Need for an 18 bed inpatient unit was obtained, and a successful fund drive was conducted which resulted in more than $1,500,000 being donated for renovation and start-up expense.

The 18 bed inpatient unit was approved as a special hospital under the Ohio CON law and was opened in April, 1981. An application was then filed for Medicare certification. In October, 1981, after much discussion and negotiation, HCFA notified Hospice of Cincinnati that the application for Medicare certification was denied, principally because they did not meet the definition of a hospital as provided in the law. We were told, "Congress would have to act before we can pay for hospice".

In December, 1981, Hospice of Cincinnati, its funds exhausted asked Bethesda Hospital to assume the financial and operating responsibilities for the future of the program. Hospice of Cincinnati failed as a freestanding community resource because it could not meet the Medicare definition of a hospital.

Mr. Chairman, hospice is a concept whose time has come. Legislative action by Congress is necessary and desirable.

VIEWS ON H.R. 5180

Our view on H.R. 5180 is that it goes beyond what is necessary for the following reasons:

1. Its design requires a hospice to be "all things to all people" once they have made the hospice election. The hospice will have to take over and pay for functions now performed by families, cancer associations, churches, and other community groups because "Medicare now pays for it." Simple examples are (1) 24 hour continuous care in a "crisis situation," and (2) a hospital bed at home, now often provided free by cancer associations, would be provided by hospice if prescribed by the physician. Those who formerly provided this service free would put their resources in areas not covered by Medicare.

2. Second, but maybe most importantly, H.R. 5180 would add significantly to the administrative cost of the health care system by adding hospice as a separate division of service in addition to existing hospital, skilled nursing, and home care divisions. This would affect HCFA, each state, Joint Commission, and each provider. A whole new set of consultants and experts will be born. The draft of Joint Commission Standards for Hospice is the first example. It is some 80 pages long.

3. The Cap is not a Cap. I am told that the Cap includes all the cost of services covered by Medicare during the last six months of life for all patients who died of cancer. It includes chemotherapy, radiation therapy, surgery, and other attempts to prolong or save lives. It does not include respite care, home care during a crisis, custodial care, and bereavement visits. The Cap is acknowledged as apples and oranges, thus 75% of the current cost was established as a limit. This does not provide any real control as patients will elect into the program at various times before death. They could have all of the costly life prolonging services and then elect into

hospice. If this really is not a Cap, then there is nothing to ensure that the hospice cost will not gravitate toward the Cap as there is no real incentive to operate in "a cost effective manner." I believe that this could result in a net increase in cost rather than a savings.

4. If the Cap is a Cap, then hospice cannot survive. The bill requires each hospice to become an insurance company, an HMO for the terminally ill. Yet there is no incentive for assuming the risks as the hospice is reimbursed at "cost or the cap whichever is less."

5. The requirement of the "hospice election" will prevent many patients from seeking hospice care simply because of their fear, founded or unfounded, of what they do not understand.

6. The bill legislates coverage for new services not now covered, including:

(a) 24 hour home care in a "crisis situation." This could be more costly than inpatient care as the staffing ratio is 1:1, as compared to approximately 3 patients to one nurse in inpatient units and, thus, is not an efficient use of resources.

(b) Respite care in an inpatient unit. There probably is need to cover a few days for relief for the family. Let the Secretary include a limited number of days (such as a maximum of five days) of such care for a terminally ill patient as a "covered service" just as the Secretary does for other services.

(c) Bereavement Visits—the bill now provides for three bereavement visits. Sometimes only a telephone call may be all that is necessary; at other times a volunteer visit may be appropriate.

(d) Custodial Care—Do you really want to provide custodial care? I personally do not believe custodial care should be paid for with federal funds.

I do support the hospice concept. Hospice care is, to terminally ill patients, a more appropriate form of care and can be a more cost effective form of care.

Hospice of Cincinnati was functioning well and could have flourished as a real community resource if it could have met the Medicare definition of a hospital. The average stay in the entire program (home care and inpatient) was 80 days. The average length of stay in the inpatient program is 8.2 days with an average cost per day of $190. This compares to an average of $259 per day for hospice home care patients who were admitted to other area hospitals when advised Medicare may not cover the inpatient stay. Hospice of Cincinnati is a more appropriate form of care, delivered cost effectively.

ALTERNATIVE PLAN

We feel that a more appropriate solution is to modify the Medicare definition of a hospital under Section 1861 (e)(1) of the law to include the definition of a Hospice. Thus, the definition would read, and I paraphrase (See Exhibit A).

"The term hospital means an institution which: (1) is primarily engaged in providing, by or under the supervision of physicians, to inpatients (a) diagnostic services and therapeutic services for medical diagnosis, treatment, and care of injured, disabled, or sick persons, or (b) rehabilitative services for the rehabilitation of injured, disabled, or sick persons, or (c) palliative and supportative services including respite care which provide physical, psychological, social and spiritual care for for terminally ill persons."

The existing definition of a home care agency already includes hospice home care.

Because hospice care would then fall under existing hospital and home care definitions, and existing codes and regulations such as life safety codes and utilization review, new regulations unthought of or duplicative regulations, would not be necessary. Also, cost effectiveness measures such as Section 223 limits for routine care and home care visits are already in place."

This alternative would let hospitals, who so choose, establish home health agencies and deliver coordinated hospice care. It would allow home health agencies to make arrangements with hospitals and/or skilled nursing facilities to provide the inpatient part of a coordinated hospice program they would develop. It would allow independent groups such as Hospice of Cincinnati, Inc. to establish independent hospices as a community resource, provided they could do so as cost effectively.

This alternative essentially provides everything that H.B. 5180 does except:

1. Bereavement visits.
2. Custodial care.
3. Homemaker services

I believe these services could all, or selectively, be added by the Secretary as covered services under existing regulations. The Secretary would then have the flexibil-

ity to determine the cost effectiveness and desirablity of including each of the above and without requiring Congressional action.

I personally believe the cost of some of these are more appropriately borne by the family, hospice volunteer, or through local fund raising efforts. As I said earlier, I personally do not believe we should attempt to pay for custodial care with federal government dollars.

CONCLUSION

Thank you for this opportunity. I want to close by reminding you of two earlier statements. First, HCFA's statement to us that "Congress will have to act before we can pay for hospice". Second, "Hospice is a concept whose time has come".

Mr. RANGEL. Thank you.

Dr. Rubin.

## STATEMENT OF JEROME L. RUBIN, M.D., MEDICAL DIRECTOR, HOSPICE OF THE MONTEREY PENINSULA

Dr. RUBIN. Thank you, Mr. Chairman.

I am Jerome Rubin, medical director, Hospice of Monterey Peninsula and I oversee the professional aspects of hospice care.

I am also executive director, Central Coast Cancer Council, which is organized to help plan for cancer resources in the area. I am speaking in support of H.R. 5180.

I will specifically comment on a freestanding facility as a backup to an active hospice home care program.

Since 1975, Hospice of the Monterey Peninsula has developed a completely integrated hospice program evolving out of the expressed needs and desires of patients. The following programs developed.

First, volunteer and patient group meetings.

Second, volunteer visitor program.

Third, multidisciplinary team.

Fourth, licensed home health agency, providing RN, nurses aide, social worker, physical therapist.

Fifth, freestanding, inpatient six-bed hospice unit licensed as a skilled nursing facility, functioning as a hospice, and currently reimbursed through existing SNF channels.

The inpatient unit was the first freestanding unit to function in California and one of the first in the country and serves as a backup to an active home care program and volunteer in-hospital program.

I am founder of Hospice of the Monterey Peninsula, initial president of the board of directors, and medical director since 1975, and continue to oversee all the professional aspects of hospice care in the community.

I am a practicing medical oncologist—cancer care specialist—and an executive director of Central Coast Cancer Council, Inc. This is an organization, funded through the National Cancer Institute and Northern California Cancer Program, involved in assessing community cancer resources, planning for cancer resources, and bringing state-of-the-art cancer care to the community.

The weekly meeting of the hospice multidisciplinary team, including physicians, nurses, volunteers, counselors, social workers would discuss all cases seen by Hospice. A significant minority of patients could no longer be cared for at home by families, required higher level of care than in existing long-term-care facilities, and

did not appropriately qualify for acute hospitalization according to locally developed guidelines.

With acute hospital beds running at close to 100 percent occupancy in our community, a separate, small facility was seen as a means of caring for these patients.

After years of discussion, certificate-of-need application and approval, licensing, and certification for providing hospice care in a separately licensed SNF was achieved.

The inpatient facility serves as a backup facility for an active home care program. The emphasis is to provide care in the environment most comfortable for patient, preferably home if this can be accomplished.

The proportion of patient days in our program in home care versus inpatient facility show the following:

February 1982: Patient days in home care, 504; patient days in inpatient hospital, 140.

Three categories of admission to the inpatient hospice unit are accepted:

First, patients admitted from home care program or from acute hospitals near the end stages of their disease, requiring more nursing care than can be provided at home, for example, pain medication, parenteral analgesic, oxygen, colostomy care, catheter, skin, respiratory care.

Second, patients who are in transition from hospital to home care where major emphasis is teaching families to help care for the patient when patient is finally at home.

Third, patients who need respite care. Families and home nurses are too exhausted with the care the patient requires at home, and respite in the inpatient facility may be advisable.

Of the last 20 patients, 85 percent were to die in the facility, requiring extensive nursing care; 15 percent were in transition to home; zero percent for respite care.

The inpatient facility has given us a unique opportunity to compare directly as possible the cost to the patient of hospitalization in an acute facility, versus the cost in an inpatient hospice unit, at a similar stage of disease.

I will comment on a direct comparison of costs of the most recent successive eight patients in hospital who were transferred to hospice.

In general, these patients had been admitted to hospital for hopefully specific reversible problems, for example intestinal obstruction due to tumor, pain due to metastatic breast cancer, nutritional insufficiency due to abdominal involvement with tumor.

I had the opportunity to observe all these patients and all required the level of nursing care received in hospital or inpatient hospice.

Except for certain procedures that have been factored out radiation therapy to a hip lesion or sternal lesion, operation for colostomy—the emphasis on care for those patients was the same in both settings—and that was the control and palliation of pain and other symptoms in patients with a limited prognosis.

The cost of care in both settings on a daily basis is listed in attachment 2.

This is one of only a few internal cost comparisons relating acute hospital care to inpatient hospice care within a contiguous time-frame where overall prognosis and aims of care had not changed, that is, the aim was to care optimally for symptoms in patients with limited prognosis.

Factors leading to increased cost in the acute facility are:

First, increased daily room rate due to higher operational overhead.

Second, increased numbers of laboratory tests, X-ray and other procedures.

Third , increased cost of certain supportive care procedures such as transfusions, antibiotics, et cetera.

Even though prognosis is limited, and goal of care is symptom control, patients in an acute care setting fall into the "next-bed snydrome."

Doctors, nurses, families will often have procedures done similar to what is being done in aggressive curative care because of their presence in the acute care environment.

Multiple procedures and tests will also make it easier to justify the patient's remaining in an acute care setting where the nursing care level is required.

The key factor, though, in supportive care, however, is the nursing staff ratio and expertise. The great majority of the cost to the patient in the inpatient hospice is for nursing salary, whereas that represents a much lower percentage of the total cost to patient in the acute setting.

Several comments are in order that hospice would be an add-on, rather than an integrated part of the medicare system. No. 1, the cap to reimbursement strongly provides incentive to a program to emphasize home care and critically look at utilization of inpatient hospice beds.

Our inpatient patient stay was less than 10 days. If patients are able to, they will be discharged to home care, where they don't require nursing care so intensively and there is no support at home, they need to be transferred to a lower level of care. That happened only in 2 out of 40 patients.

No. 2, upgrading of nursing expertise and inpatient units is continuously being done, such that most complications can be handled at an inpatient hospice. Only 1 of our last 40 patients had to be readmitted to an acute-care facility.

Most complications can be cared for at the inpatient hospice.

Three, the length of stay must be kept reasonable at a high level of nursing care. Family physicians must be educated about the purpose of the inpatient hospice and understand the level of nursing expertise and also that if such intensive level of nursing care is no longer necessary, that the patient can go back into the home care program or to a lower level of care.

Legislation is needed now to accomplish several things. With appropriate levels of reimbursement, adequate standards for accreditation and licensing hospices will take place.

This is important so that existing developing programs will not have to fit in existing licensing categories if not appropriate, but can function with standard understanding of hospice care.

Hospice has been a grassroots movement that has quickly and appropriately become integrated into the medical care delivery system. For it to continue to develop, appropriate recognition of its quality and cost effectiveness must lead to adequate reimbursement as soon as possible.

Thank you for your consideration.

[The prepared statement follows:]

STATEMENT OF DR. JEROME L. RUBIN, MEDICAL DIRECTOR, HOSPICE OF THE MONTEREY PENINSULA, AND EXECUTIVE DIRECTOR, CENTRAL COAST CANCER COUNCIL, INC.

1. INTEGRATED HOSPICE PROGRAM—HISTORY

Since 1975, Hospice of the Monterey Peninsula has developed a completely integrated hospice program evolving out of the expressed needs and desires of patients. The following programs developed.

1. Volunteer and patient group meetings.
2. Volunteer visitor program.
3. Multidisciplinary Team.
4. Licensed home health agency, providing RN, nurses aid, social worker, physical therapist.
5. Freestanding, inpatient 6-bed hospice unit licensed as a skilled nursing facility, functioning as a hospice and currently reimbursed through existing SNF channels.

The inpatient unit was the first freestanding unit to function in California and one of the first in the country and serves as a backup to an active home care program and volunteer in-hospital program.

2. MEDICAL DIRECTOR BACKGROUND

I am founder of Hospice of the Monterey Peninsula, initial president of the Board of Directors, and Medical Director since 1975, and continue to oversee all the professional aspects of hospice care in the community. I am a practicing medical oncologist (cancer care specialist) and am Executive Director of Central Coast Cancer Council, Inc. This is an organization, funded through the National Cancer Institute and Northern California Cancer Program, involved in assessing community cancer resources, planning for cancer resources and bringing state of the art cancer care to the community.

3. DEVELOPMENT OF INPATIENT FACILITY—FREESTANDING OUT OF NEEDS OF EXISTING PROGRAM

The weekly meeting of the Hospice Multidisciplinary Team, including physicians, nurses, volunteers, counselors, social workers would discuss all cases seen by Hospice. A significant minority of patients could no longer be cared for at home by families, required higher level of care than in existing long-term care facilities, and did not appropriately qualify for acute hospitalization according to locally developed guidelines. With acute hopsital beds running at close to 100 percent occupancy in our community, a separate, small facility was seen as a means of caring for these patients. After years of discussion, certificate of need application and approval, licensing and certification for providing hospice care in a separately licensed SNF was achieved.

The inpatient facility serves as a backup facility for an active home care program. The emphasis is to provide care in the environment most comfortable for patient, preferably home if this can be accomplished.

The proportion of patient days in our program in home care versus inpatient facility show the following:

| February 1982: | |
|---|---|
| Patient days in home care | 504 |
| Patient days in inpatient hospice unit | 140 |

4. PRIORITIES OF ADMISSIONS TO INPATIENT HOSPICE UNIT

Three categories of admission to the inpatient hospice unit are accepted:

i. Patients admitted from home care program or from acute hospitals near the end stages of their disease, requiring more nursing care than can be provided at

home, e.g., pain medication, parenteral analgesic, oxygen, colostomy care, catheter, skin, respiratory care.

ii. Patients who are in transition from hospital to home care where major emphasis is teaching families to help care for the patient when patient is finally at home.

iii. Patients who need respite care. Families and home nurses are too exhausted with the care the patient requires at home, and respite in the inpatient facility may be advisable.

Of the last twenty patients, 85 percent were to die in the facility, requiring extensive nursing care; 15 percent were in transition to home; 0 percent for respite care.

### 5. COST STUDIES

The "Summary and Statement of Conclusions of Cost and Fiscal Impact Analysis of Proposed National Hospice Reimbursement Bill" commissioned by the Warner-Lambert Foundation suggests significant cost reductions to the Medicare program of hospice services were recognized and reimbursed.

Most of the existing studies document cost of hospice care and compare to sets of control patients having received "traditional" care in the last 3-6 months of life.

The cost to the patient of our home care program has been analyzed in the California Department of Health Services, Report to the 1980 California Legislature on the Hospice Project, 1980. These costs are in keeping with others that have been presented to you.

The inpatient facility has given us a unique opportunity to compare directly as possible the cost to the patient of hospitalization in an acute facility versus the cost in an inpatient hospice unit, at a similar stage of disease. I will comment on a direct comparison of costs of the most recent successive 8 patients in hospital who were transferred to Hospice.

In general, these patients had been admitted to hospital for hopefully specific reversible problems, e.g., intestinal obstruction due to tumor, pain due to metastatic breast cancer, nutritional insufficiency due to abdominal involvement with tumor. I had the opportunity to observe all these patients and all required the level of nursing care received in hospital or inpatient hospice. Except for certain procedures that have been factored out (radiation therapy to a hip lesion or sternal lesion, operation for colostomy) the emphasis on care for those patients was the same in both settings—control and palliation of pain and other symptoms in patients with a limited prognosis. The cost of care in both settings on a daily basis is listed in Attachment 2.

This is one of only a few internal cost comparisons relating acute hospital care to inpatient hospice care within a contiguous time frame where overall prognosis and aims of care had not changed, i.e., the aim was to care optimally for symptoms in patients with limited prognosis.

Factors leading to increased cost in the acute facility are:

1. Increased daily room rate due to higher operational overhead.
2. Increased numbers of laboratory tests, x-ray and other procedures.
3. Increased cost of certain supportive care procedures such as transfusions, antibiotics, etc.

Even though prognosis is limited, and goal of care is symptom control, patients in an acute care setting fall into the "next bed syndrome." Doctors, nurses, families will often have procedures done similar to what is being done in aggressive curative care because of their presence in the acute care environment. Multiple procedures and tests will also make it easier to justify the patient's remaining in an acute care setting where the nursing care level is required.

The key factor in supportive care, however, is the nursing staff ratio and expertise. The great majority of the cost to the patient in the inpatient hospice is for nursing salary, whereas that represents a much lower percentage of the total cost to patient in the acute setting.

### 6. NEED FOR LEGISLATION

This legislation is needed now to accomplish several things.

1. With appropriate levels of reimbursement, adequate standards for accreditation and licensing hospices will take place. This is important so that existing developing programs will not have to fit in existing licensing categories if not appropriate, but can function with standards understanding of hospice care.

2. Hospice has been a grass roots movement that has quickly and appropriately become integrated into the medical care delivery system. For it to continue to develop, appropriate recognition of its quality and cost effectiveness must lead to adequate reimbursement as soon as possible.

SUMMARY

Hospice care is being appropriately integrated into the medical care delivery system. It provides an appropriate alternative care for patients with limited prognosis who require expert attention aimed at pain and symptom control.

Hospice home care has shown significant cost savings to the Medicare program by decreasing days in hospital.

Similarly, when inpatient care is necessary, inpatient hospice would represent a significant savings to the Medicare program.

## ATTACHMENT 1—COST COMPARISON OF ACUTE HOSPITAL TO INPATIENT HOSPICE

[Cost of care for 8 successive patients cared for in acute hospital who were transferred directly to hospice requiring and receiving same level of nursing care]

| | Daily cost in acute hospital | Daily cost in acute hospital excluding cost of radiation, surgery | Daily cost in hospice |
|---|---|---|---|
| Patient: | | | |
| 1 | $374 | $270 | $201 |
| 2 | 346 | 297 | 202 |
| 3 | 488 | 467 | 209 |
| 4 | 287 | 287 | 202 |
| 5 | 341 | 341 | 204 |
| 6 | 607 | 606 | 203 |
| 7 | 403 | 403 | 205 |
| 8 | 357 | 357 | 201 |
| Average | 400 | 378 | 203 |

## ATTACHMENT 2.—*Cost study of inpatient unit*

| Employee costs: | *Total* |
|---|---|
| Salaries: | |
| 01 Permanent employees: | |
| Medical director | $50,000 |
| Director of patient care | 20,000 |
| Hospice nurse (3 at $20,000) | 60,000 |
| Hospice caregiver (3 at $14,412) | 43,236 |
| Cook (2,080 hrs at $3.80 hr) | 7,904 |
| Housekeeper (at $3.75 hr) | 7,800 |
| Receptionist | 9,300 |
| Total permanent employees | 198,240 |
| 02 Part/time employees: | |
| Hospice nurse (2/3,280 hrs at $9.60 hr) | 31,488 |
| Hospice caregiver (3/3,280 hrs at $6.90 hr) | 22,632 |
| Cook (1,100 hrs at $3.80 hr) | 4,180 |
| Billing clerk (20 hrs at $6.00 hr) | 6,240 |
| Building maintenance engineer (75 percent of $825 month) | 7,425 |
| Total part-time employees | 71,965 |
| Total salaries | 270,205 |
| Fringe benefits: | |
| 04 Pension plan (5 percent gross payroll) | 13,510 |
| 05 Social security (6.70 percent in lieu of) | 16,763 |
| 06 State unemployment insurance (3.5 percent $6,000) | 4,136 |

| | | |
|---|---|---|
| 07 | Worker's compensation insurance | 19,615 |
| 08 | Health insurance (estimate 11 at $80/mo.) | 10,560 |
| | Total fringe benefits | 64,584 |
| | Total employee benefits | 334,789 |
| Operating and maintenance: | | |
| 10 | Training | 1,500 |
| 11 | Travel (4,000 miles at .25) | 1,000 |
| 12 | Consultations: | |
| | Dietician (at $125 monthly) | 1,500 |
| | Occupational therapist (8 hr per week at $25 per hr) | 2,400 |
| | Physical therapist (5 hr per week at $40 per hr) | 10,400 |
| | Total consultations | 14,400 |
| 15 | Office expense—postage | 300 |
| 16 | Office expense—other: Expendable office supplies, maintenance and equipment | 1,000 |
| 17 | Books and periodicals: Newspaper, magazines, patient use, nursing publications | 1,000 |
| 18 | Duplication and printing: | |
| | Miscellaneous forms | 500 |
| | Name pins and identification | 200 |
| | Copier usage | 200 |
| | Total duplication and printing | 900 |
| 20 | Household—food ($5 per day) | 10,950 |
| 21 | Household—supplies | 2,000 |
| 22 | Pool supply and maintenance | 1,200 |
| 23 | Medical supplies: Oxygen, medications, etc. | 4,000 |
| 24 | Grounds—Supply and maintenance | 3,000 |
| | Gardener (at $400 mo) | 4,800 |
| | Total grounds | 7,800 |
| 25 | Telephone: | |
| | Monthly service | 2,000 |
| | Pager for coordinator | 300 |
| | Total telephone | 2,300 |
| 26 | Utilities: | |
| | P.G.&E. (90 percent) | 2,000 |
| | Disposal (90 percent) | 300 |
| | Cal Am water (90) | 200 |

| | | |
|---|---|---|
| | Bottled water | 300 |
| | TV cable | 300 |
| | Total utilities | 3,100 |
| 27 | Fees and licenses | 1,500 |
| 30 | Mortgage payments (90 percent): | |
| | Monterey Saving & Loan | 22,896 |
| | Ruben et al | 3,690 |
| | Total mortgage payments | 26,586 |
| 33 | Insurance (90 percent): | |
| | Building contents | 927 |
| | Professional liability umbrella | 1,800 |
| | Total insurance | 2,727 |
| | Total operating and maintenance | 82,163 |
| Capital outlay: | | |
| 51 | Building: Electrical/plumbing repairs | 10,000 |
| 53 | Furniture and equipment: | |
| | Nursing station—desk | 300 |
| | Nursing station—typewriter | 700 |
| | Nursing station—file cabinet | 195 |
| | Industrial vacuum cleaner | 300 |
| | Examining room: | |
| | Examining table | 1,000 |
| | Supply cabinet | 200 |
| | Stool | 95 |
| | Lamp | 100 |
| | Total furniture and equipment | 2,890 |
| | Total capital outlay | 12,890 |
| | Total cost | 429,842 |

Mr. RANGEL. Thank you, Doctor.

Mrs. Fremgen, Illinois State Hospice Association.

## STATEMENT OF SUE FREMGEN, DIRECTOR AT LARGE, ILLINOIS STATE HOSPICE ASSOCIATION, AND PRESIDENT, ST. THOMAS HOSPICE, DARIEN, ILL.

Ms. FREMGEN. Mr. Chairman, I would like to request that my full written testimony be made a part of the record.

Mr. RANGEL. Without objection.

Ms. FREMGEN. I am grateful to testify in support of hospice bill 5180. I am a director at large on the Illinois State Hospice Organization Board and president of St. Thomas Hospice in Darien, Ill., which has been in operation for 2 years.

As delegated representative of the Illinois State Hospice Organization, I am here to present the position of the State members concerning the proposed legislation.

The Illinois State Hospice Organization stands in support of the hospice bill, H.R. 5180. A great deal of study has preceded our decision.

We believe that this bill deserves the support of our legislators in Washington.

Some suggestions for refinement do exist among the 34 providers of hospice care in the State of Illinois.

Mr. Chairman, I would like to ask you if it would be appropriate at this time to comment on certain sections of the bill even though they are contained in written testimony?

Mr. RANGEL. The comments are in your written testimony. We have read them.

Ms. FREMGEN. Thank you, Mr. Chairman.

Mr. RANGEL. I would personally see that the author of the bill receives it, it will be a part of the record, and many of them are recommendations that I am certain he would agree with.

Ms. FREMGEN. Thank you very much. I just want to make one other point. Volunteer hospice organizations in Illinois that utilize existing facilities to provide hospice care to their communities have raised the issue that such organizations are not without administrative costs.

The present hospice bill does not address reimbursement for administrative expenses for organizations that do not provide direct care.

Obviously, there is no medium for volunteer organizations who are not contractually affiliated with a hospital or home care agency to absorb administrative expenses.

The continued survival of these volunteer organizations, who have given invaluable service is open to question. The members of the Illinois State Hospice Organization appreciate the work of this committee and its efforts to foster the growth of what we know to be compassionate care for the terminally ill patients and their families.

The hospice care concept has been well received in the United States, and we feel your work will assist its further development. We urge this committee to pass H.R. 5180 this year and I sincerely thank you for the opportunity to present our views.

[The prepared statement follows:]

STATEMENT OF SUE FREMGEN, DIRECTOR AT LARGE, ILLINOIS STATE HOSPICE ORGANIZATION

I, Sue Fremgen, am grateful for the opportunity to testify in favor of the Hospice Bill H.R. 5180. I am Director at Large on Illinois State Hospice Organization Board and President of St. Thomas Hospice in Darien, Illinois, which has been in operation for two years. As delegated representative of the Illinois State Hospice Organization, I am here to present the position of the state members concerning the proposed legislation.

POSITION STATEMENT

The Illinois State Hospice Organization stands in support of the Hospice Bill H.R. 5180. A great deal of study has preceded our decision. We believe that this bill deserves the support of our legislators in Washington.

Areas of concern exist among the thirty-four providers of hospice care in the State of Illinois. We want to adddress these concerns so that an awarenes of the needs of existing independent, not-for-profit, volunteer hospice programs, as well as the needs of home health and hospital-based programs, are taken into consideration.

In addressing these concerns, I will be referring to the December, 1981, "Section-By-Section Summary of Hospice Bill H.R. 5180—S. 1958".

AREAS OF CONCERN

The first area of concern relates to the 180 day election. Section 2, Paragraph 1, points out that an individual would be entitled to elect to receive hospice care

during two periods of 180 days each in lieu of other Medicare benefits. It further states that an individial could revoke election of hospice care during the 180 day period. . . If an individual revoked the election, the remaining portion of the 180 days would be forfeited.

We recognize that revoking the election of hospice care could indeed happen in the throes of denial when a person is terminally ill, and for this reason we are concerned about the forfeiture of the remaining days of the 180 day period.

We would like consideration given to not including a forfeiture of remaining days, even though there exists an election of another 180 day period.

The second area of concern deals with certification. Section 2, Paragraph 1, reads "Payment for hospice services are made if the attending physician and the medical director or physician member of the hospice team certify that the individual is termenally ill (later defined as medical prognosis of six months or less to live) and such prognosis is recertified at the beginning of a second 180 day period."

The requirement that a physician "certify" terminal illness defined as a medical prognosis of six months or less to live is viewed as certifying a definitive time of death. It is our opinion that certification would be more palatable to the physician who is reluctant to define a duration of remaining days for the terminal patient if the statement of certification read as follows: "that a patient has a terminal illness and appears to have a poor, short-term prognosis for recovery" or a comparable statement of this nature.

The third area of concern is not directly addressed in the Section-By-Section Summary but has been raised as an issue by those Illinois hospice programs that consist primarily of volunteers and who have been providing hospice services to their respective communities by utilizing existing agencies. This type of hospice service is not without administrative cost. The present Hospice Bill does not address reimbursement for administrative expenses. Hospice programs that are hospital-based or home care-based have up to this point absorbed indirect administrative costs. Obviously there is no medium for volunteer organizations who are not contractually affiliated with a hospital or home care agency to absorb administrative expenses. The continued survival of these volunteer organizations who have given invaluable service is threatened.

The members of the Illinois State Hospice Organization appreciate the work of this committee and its efforts to foster the growth of what we know to be compassionate care for our terminally ill patients and their families. The hospice care concept has been well received in the United States, and we feel your work will assist its further development. We sincerely thank you for the opportunity to present our views.

Mr. RANGEL. Thank you.

Mr. Duncan?

Mr. DUNCAN. I have no particular questions, other than to thank the panel. I think it's been one of the better panels that we have heard from recently.

You have presented broad views and very helpful views.

I would like to know if any of you have a cost analysis of what the bill would cost? I think you mentioned that you knew how to estimate the costs?

Mr. LEFKOWITZ. Yes, Mr. Duncan. We do have the costs. In fact, we submitted them to HCFA. We do commit them on a quarterly basis.

Mr. DUNCAN. Do you think we will save money, will it cost more than we are now spending?

Mr. LEFKOWITZ. Our cost experience indicates to us we will definitely save money. But as I testified, I do not think that should be the criterion.

Mr. DUNCAN. We must consider those things. I support your initiative. I think, whether it is a criterion or not, that we must consider those things in the House, because cost is what all programs ride upon.

But I do thank you very much. Thank you, Mr. Chairman.

Mr. BROOKS. Mr. Duncan, our average stay is 8.2 days. The patients are saying in the entire program for approximately 80 days. The 8.2 days they are spending in the hospice inpatient unit is at a cost of $190 per day. This is about 25 percent less expensive than hospice home care patients who are going to other hospitals, because at this time we cannot assure them reimbursement will follow.

So they are going to other area hospitals, and it is costing about $70 a day more on average for the reasons that the doctor presented in his testimony.

Mr. DUNCAN. Thank you. Thank you, Mr. Chairman.

[The following was submitted for the record:]

URBANA, ILL., *March 22, 1982.*

Re H.R. 5180.

Hon. DANIEL ROSTENKOWSKI,
*Rayburn House Office Building,*
*U.S. House of Representatives, Washington, D.C.*

DEAR REPRESENTATIVE ROSTENKOWSKI: This letter comes as a word of gratitude for your having arranged for an Illinois State Hospice Organization representative to testify at the hearing called by Representative Andy Jacobs concerning the Hospice Bill on March 25, 1982. The deadline regarding this hearing reached us post fact, and without your assistance we would not have been able to present a testimony. Our representative is Sue Fremgen, a Director at Large for Ilinois State Hospice Organization.

In addition, I appeal to you specifically to elicit your active cosponsorship of H.R. 5180. Our Illinois State Hospice Organization has reviewed this bill and finds that we are in agreement, generally speaking, concerning H.R. 5180. As provider representatives, we urge your endorsement of H.R. 5180 based on its cost effectiveness.

Being familiar with the origin of the Health and Human Services grant that was awarded to 26 demonstration sites in early 1979 (but to no hospice in Illinois), I believe the demonstration projects have merit, especially since through their analysis it will become apparent that hospice care is cost effective for terminal patients of all ages. However, at this point H.R. 5180 asks only that hospice care be included in Medicare coverage for those persons already eligible for Medicare benefits.

Many programs have stayed in existence primarily because of the dedication of and commitment made by staff and volunteers, despite the lack of reimbursement for many services that have enabled terminal patients to remain at home who would otherwise have had to be institutionalized. The following case representatively cites an instance where hospice care has proven not only humane but also cost effective.

A 56-year-old man was diagnosed with carcinoma of the breast in August, 1979, and in March, 1980, metastases to the chest and spine were discovered which resulted in quadraparesis at a C7 level. Essentially this rendered him dependent for activities of daily living and a prospective candidate for institutionalization. Comparable progressive disease processes require institutionalization for longer periods of time. From August 3 to September 11, 1981, this person's disease progressed more rapidly, and he required two regular hospital admissions totalling 30 days.

On September 11, 1982, he was admitted to our hospice program and transferred from a regular hospital room to our Palliative Care Unit with a limited prognosis of less than six months. During his stay, a family conference was held to plan for discharge, which was attended by the patient, his daughter and son-in-law, the hospice clinical coordinator, a home health nurse, social worker, volunteer coordinator, pastoral care associate, dietitian, physical therapist, and occupational therapist. He was discharged to his daughter's home on September 19, 1981, and with the varied support of 13 volunteers and weekly visits by the home health nurse, the patient was able to remain at the home for five months without a single hospital admission, even though his daughter and son-in-law were both employed full time.

Albeit this is the situation of one of the 108 patients and families we have served since July 7, 1980, it is representative of most of the patients/families we have served. In providing hospice care we have shifted most of the care of the patient's last days/months of living into the home.

Again, I personally request your endorsement of this bill. Inclusion of hospice coverage in Medicare, as in H.R. 5180 and S. 1958, will help insure the continued exist-

ence of hospice services which currently are operating at a deficit. Coverage for the 70 percent of terminally ill patients who are over 65 years of age is essential!

Sincerely,

SR. BETTE MANIATIS,
*Director, Mercy Hospice Care Program,*
*President, Illinois State Hospice Organization.*

Mr. RANGEL. Thank you.

Are all of these for-profit institutions that you represent?

Ms. DEVORE. No, none of them are.

Mr. RANGEL. In Cabrini, have you had the opportunity to see the comaprison charts offered by other witnesses as relates to hospital costs here today, and hospices costs per day?

Mr. LEFKOWITZ. Yes.

Mr. RANGEL. Does Cabrini compare favorably on the other?

Mr. LEFKOWITZ. Very favorably. The only differences are, New York City is a very high cost area. Other than that, we compare very favorably in length of stay, type of treatment, and so forth.

Mr. RANGEL. That answers your question, Mr. Duncan, why we do not deal with costs in our city.

Thank you very much. We may have other questions to be submitted as relates to utilization of volunteers, the daily cost as well as the average length of stay. The record will remain open. We hope we can get some answers.

Next panel.

Neil Hollander, Blue Cross and Blue Shield; Washington Business Group on Health, Willis B. Goldbeck, executive director; Travelers Insurance Companies, Robert M. Neiswanger; and Warner-Lambert Co., Ronald E. Zier, vice president, Public Affairs, accompanied by Ewart Thomas.

We have a problem here because in looking over some of the written testimony, none of this will be able to fit into the so-called 5-minute rule. With the understanding that the full statements will appear in the record, I will ask the witnesses when they can highlight their testimony.

And without objection, the full statements will appear in the record.

We will start off with Blue Shield.

## STATEMENT OF NEIL HOLLANDER, VICE PRESIDENT, HEALTH CARE SERVICES, BLUE CROSS AND BLUE SHIELD ASSOCIATIONS

Mr. HOLLANDER. Mr. Chairman, I am here today representing the Blue Cross and Blue Shield Associations.

We have probably more experience in paying for hospice care than any other third party in the country today. We have been involved with hospice almost from the beginning of the movement. Our actions have been based upon several basic points.

First, that the hospice represents an exciting opportunity for integrating a more compassionate way of caring for terminally ill patients into the health care financing structure. That is the kind of care that should be part of the fabric of our health care system.

Second, that home care, coordination of services, and the critical involvement of volunteers represents an important link between medical and nursing care and active community participation.

Third, that we ought to undertake carefully developed hospice demonstration projects.

Fourth, that our plans pay for hospice care as an extension of existing benefits focusing on hospice care as a coordinating base for service delivery.

Mr. Chairman, in our experience to date, we now have more than 35 plans which have formal programs underway. This leads us to believe given the wide diversity of hospice care and all of the questions which remain unanswered, that it remains the proper course to continue moving forward with demonstration projects.

Consequently, we believe it would be unwise to proceed at this time with the legislation as far reaching as H.R. 5180.

It would seem more judicious to us to extend experimental funding as it is warranted to assist hospice programs involved in the HCFA demonstration project until the Congress can take full advantage of the results and recommendations of that multimillion dollar evaluation.

Aside from the timing of the legislation, we believe several of the provisions in the bill should bear further scrutiny. We are troubled by the provision that seems to require hospice patients to waive certain rights to medicare benefits beyond those hospice services relating to their terminal diagnosis. If this provision inhibits access to necessary medical care, it could jeopardize the quality of care.

Also we doubt such a provision could be effectively administered at this time.

A second concern lies with the proposed reimbursement methodology.

The methodology averages costs for services that may be quite unrepresentative of those actually received by hospice patients. The methodology may both overstate the appropriate costs of hospice home-care services in the short term, and encourage hospice care providers to spend up to the caps.

A third concern is the two 180-day periods of care. Our experience is that 360 days is unnecessary and may be prone to misuse. Utilization of hospice care may well be stimulated by the availability of coverage. Every caution, therefore, must be taken to assure that utilization is appropriate and medically necessary.

At the outset of my comments, I noted that the Blue Cross and Blue Shield organizations believe that hospice care is most viable if it is an integral component of the health care system. We have serious reservations therefore with the legislative definition which appears to establish hospice programs as independent of other health care providers.

The proposed definition also requires that hospice providers either offer a full complement of services or make arrangements with other local hospice programs for services that they cannot provide themselves.

We fear that such a definition will foster the development of multifunction freestanding facilities, and the decline of community-based hospice programs.

It can be argued that this legislation would provide a dependable source of reimbursement for many high quality hospice care providers. We are concerned, however, that in the absence of accreditation or licensure in most States, the bill could support inefficient,

less responsible providers as well. In addition, a dramatically increased source of income could support the proliferation of independent hospice facilities and perhaps unnecessary capital investment.

In summary, Mr. Chairman, before expanding medicare benefits further, we believe the Congress should have reasonable assurances that the cost and utilization of these benefits will be within manageable limits. We therefore believe it is important to explore further alternative ways to cover hospice care for medicare beneficiaries.

As for the interim, we do not believe that the absence of legislation prevents access to necessary medical care.

Mr. Chairman, we appreciate the opportunity to appear before you and we will be pleased to answer any questions you might have. Thank you.

[The prepared statement follows:]

STATEMENT OF THE BLUE CROSS AND BLUE SHIELD ASSOCIATIONS, AS PRESENTED BY NEIL HOLLANDER, EXECUTIVE DIRECTOR

Mr. Chairman and members of the Committee. I am Neil Hollander, Executive Director for Health Care Services of the Blue Cross and Blue Shield Associations, the national coordinating agency for the 109 Blue Cross and Blue Shield Plans in the United States and Puerto Rico. Today Blue Cross and Blue Shield Plans serve over 86 million members under private programs and an additional 26 million people under government programs.

The views I present reflect the knowledge and experience gained by the Blue Cross and Blue Shield organizations through our administration of both government and privately underwritten health care financing programs and through local involvement in planning and developing hospice care programs. Collectively, Blue Cross and Blue Shield Plans have more experience in paying for hospice care than any other third-party payor.

OVERVIEW

The Blue Cross and Blue Shield Associations, and our member Plans, have been involved in hospice care program development and have advocated sound implementation of hospice care since 1977. In 1978, the Associations adopted "An Initial Statement of Policy on Hospice Care and Payment for Hospice Services." Although that policy was adopted at a time when Plan activity in this area was quite new, it continues to be a valid expression of our policy. The hospice policy statement reflects a constructive approach for integrating a more compassionate way of caring for terminally ill patients into our health care financing structure. It emphasizes the importance of home care and coordination of services. It gives volunteer services a critical role in the delivery of hospice care, providing an organized link between medical and nursing care and active community participation.

The Blue Cross and Blue Shield organizations view hospice not as an addition to the health care system, but, rather, as a reorientation of the care normally provided to terminally ill patients. The Associations' policy statement encourages Plans to undertake hospice demonstration programs. The statement recommends that Plans pay for hospice care as an extension of existing benefits, focusing on home care as the coordinating base for service delivery.

Our experience with the 1978 policy tells us that the demonstration approach for introducing coverage for hospice care has great merit. Indeed, we still advocate this approach to Blue Cross and Blue Shield Plans and would do so for the Medicare program as well until results are obtained that point us in a different direction. Consequently, we believe it would be unwise to move ahead with legislation as far reaching and potentially indelible in its approach as H.R. 5180. Before discussing H.R. 5180 in more detail, we want to share some of the experiences of Blue Cross and Blue Shield Plans.

BLUE CROSS BLUE SHIELD PLAN EXPERIENCE

More than thirty-five Blue Cross and Blue Shield Plans have implemented the guidelines put forth in the Associations' 1978 policy. This number, may to some extent, understate the actual involvement of Plans in hospice care. Many Plans that have not yet implemented formal hospice programs offer extensive home care and extended care coverage. Through such coverage, many more Plans make hospice and other services available to their subscribers.

The majority of Plans offer coverage on a demonstration basis, focusing primarily on home care and inpatient coverage. Plan programs vary, as one would expect, given the wide diversity of hospice care providers and programs. In fact, an investigative study we did with the American Hospital Association and the National Hospice Organization revealed that the twenty hospice care programs observed had almost twenty different ways of organizing themselves and the delivery of care.

As a result of this diversity some Plans pay only for hospice-home care; others also pay for hospice care provided in special inpatient facilities. Some Plans expect hospice programs to make extensive use of volunteer manpower while other Plans will expect programs to hire additional personnel to meet these staff functions. Experimental arrangements have been developed to provide payment for services not typically in the third-party payors' domain—such as bereavement counseling and social welfare services.

The great differences among the Plan programs makes it difficult to draw quick generalizations. We are, however, beginning to collect preliminary experience-based data. Analysis of this experience has led us to a conclusion that hospice care can be cost effective when implemented carefully. Programs that organize local community resources—augmenting existing services only when necessary—are most successful.

We have found, for example, that hospice programs which rely primarily upon inpatient care result in costs much like those of traditional inpatient care. The Washington, D.C. Blue Cross Plan, for example, finds that average per patient costs for Blue Cross subscribers at the Washington Home's Hospice Program, an extended care facility hospice program, to be approximately $8,000—an amount comparable to the cost of caring for terminally ill patients in area hospitals.

Use of home care services, our experience indicates, results in lower program costs. Depending on the number of inpatient admissions required by each patient, home care hospice programs report costs averaging between $2,500 and $5,000. Average costs for 681 patients served by the Connecticut Hospice ranged from $1,257 for patients receiving only home care services to $18,927 for patients requiring home care and up to 6 inpatient admissions.

A second conclusion we can draw is that the hospice movement is solidifying and growing stronger. Hospice programs and providers are gaining experience and expertise not only in managing care, but in managing the financial aspects of care delivery as well. We see the promise of future growth, development and adaptation of the hospice concept of care as quite bright. We believe that under proper circumstances, hospice care can prove less costly than traditional inpatient care for terminally ill patients. We are not convinced, however, that at this stage of hospice development, the bill before you, H.R. 5180, is an appropriate way to foster sound growth and delivery of hospice care services.

The timing of this bill is one of our major concerns. In the past, well intentioned introduction of new services into Medicare without a firm understanding of how to make good ideas work has resulted in unexpected and substantial expenditures. In the case of hospice care, it would seem more judicious to extend funding for hospice programs involved in the HFCA demonstration project until the Congress can take full advantage of the results and recommendations of the multi-million dollar project evaluation. The evaluation is sponsored jointly by HCFA and the Robert Wood Johnson Foundation. The HCFA hospice demonstrations promise solid evidence of the appropriate costs associated with hospice care and the appropriate manner of providing care.

The analytical results of the demonstration will yield a strong foundation on which to base legislative proposals. Acting without this information may put Congress in the same position it was in prior to expanding Medicare coverage for end stage renal disease.

The expansion of Medicare to include coverage for ESRD patients was approved when there was essentially no data available on program costs. The cost of this program has increased at an unexpected rate. Although we do not question the importance of the program, we believe we should consider ourselves forwarned and act cautiously before expanding the Medicare program into new service areas.

Aside from the timing of this legislation, we have serious concerns about several of the provisions included in H.R. 5180.

First, we are troubled by the provision that requires hospice patients to waive certain rights to Medicare benefits beyond those hospice services related to their terminal diagnosis. Terminally ill individuals, like all others, break bones, catch colds and otherwise require care for conditions unrelated to their primary diagnosis. If this provision inhibits access to necessary medical care, it could jeopardize the quality of care. In any event, we doubt such a provision could be administered effectively at this time. Eligibility cannot be determined by a provider quickly enough to prevent utilization of non-covered care. Non-covered care is likely to be provided, leaving providers with retroactive denials of payment.

Our second area of concern lies with the proposed reimbursement methodology. The reimbursement methodology appears to average the total of inpatient and home care costs for all services received by terminally ill patients in the 12 month base period. In so doing, the methodology averages costs for services that may be quite unrepresentative of those services actually received by hospice patients. The resulting number is then subjected to a regional adjustment. The reimbursement methodology may overstate the appropriate costs of hospice-home care services and increase hospice costs generally by encouraging providers to spend up to the caps.

A third concern is the two 180 day periods of care. In our experience, a common length of stay for hospice care ranges between thirty and thirty-five days.

Some patients, of course, do require more, and home care lengths of stay of 70–75 days are not uncommon. However, we find 360 days, as provided in this legislation, to be quite excessive. Two periods of up to 180 days of care each, to be used in either home care of short stay inpatient care is overly generous and utilization of hospice care may well be stimulated by the availability of coverage. Every caution must be taken to assure that utilization is appropriately controlled and medically necessary.

At the outset of my comments I noted that the Blue Cross and Blue Shield organizations believe that hospice care is most viable if it is an integral component of the health care system. We take strong issue with a conception of hospice that could set it off from the rest of the delivery system. The definition of a hospice program offered in the legislation is one which is "primarily engaged in providing care and services . . . directly or through arrangements with other hospice programs." The legislative definition appears to establish hospice programs as independent of other health care providers, as opposed to integral parts of an existing system.

The proposed definition also requires that hospice providers either offer a full complement of services or make arrangements with other local hospice programs, perhaps competitors, for services they cannot provide themselves. We fear that such a definition will foster the development of multi-function freestanding facilities and the decline of community based hospice programs closely tied to existing home care and inpatient services. In contrast, Blue Cross and Blue Shield Plans emphasize home care, wherever possible, as the central and coordinating locus of hospice responsibility. Through home care as a base, hospice programs should weave together existing services as effectively as possible.

It can be argued that the legislative definition of hospice care would provide a dependable source of reimbursement for many high quality hospice care providers. The Blue Cross and Blue Shield organizations are concerned, however, that in the absence of hospice accreditation or licensure in most states, H.R. 5180 could support inefficient, less responsible providers as well.

Finally, expansion of Medicare to include the breadth of services listed in this legislation creates a troublesome precedent. If Medicare covers non-medical support services for cancer victims and their families, would it not also be appropriate to cover such services for other patients, such as stroke victims whose illness often creates comparable strains on patients and their families? What of the widow whose husband dies of a sudden heart attack: Couldn't she be in as much need of counseling and support as the widow of the person who dies from a more protracted illness? These are difficult questions for which there are not easy answers, but they are questions that must be faced nonetheless if benefits covering extensive social and family services are added to the Medicare program.

In summary, before expanding Medicare benefits further, we believe the Congress should have reasonable assurance that the cost and utilization of these benefits will be within manageable limits. We therefore urge the Congress to explore further alternative ways to cover hospice care for Medicare beneficiaries.

As for the interim, we do not believe that the absence of legislation prevents access to necessary medical care. With the exception of some non-medical services, such as custodial care, bereavement counseling and dietary assistance, most needed services are now covered by Medicare and supplemental third-party coverage. Many

services not directly covered, such as pastoral counseling and dietary assistance are typically reimbursed as overhead expenses of the hospice facility or home care provider. Those remaining services, such as social or family counseling, have traditionally been provided by hospice volunteers.

In conclusion, we wish to emphasize our support for hospice care and our hope that it continues to grow and develop. Although the experiences of individual Plans are obviously mixed, most Plans are encouraged and enthusiastic about their hospice programs. Much like the HCFA demonstrations, Plan programs are carefully negotiated with local providers. Agreements for data collectionon all program facets are drawn up and reimbursement schedules are developed individually. We would urge the Committee to be sure that any legislative proposal also provides for similar program controls.

Mr. Chairman, we appreciate the opportunity to appear before you to present our views. We will be pleased to answer any questions or provide any assistance the Committee may require in its deliberations on this important legislation.

[Attachment]

## Blue Cross Association and Blue Shield Association Initial Statement on Hospice Care and Payment for Hospice Services

(Approved November 8, 1978, by the Boards of the Blue Cross and Blue Shield Associations)

### INTRODUCTION

In 1974 there was only one formal hospice care program in the United States. Four years later, in 1978, there are over one hundred in varius stages of operation or development. A 1978 survey of hospice programs conducted by the National Hospice Organization received 144 responses, half of which were from providers already delivering some form of hospice care. Nearly all the rest of the respondents anticipated providing such care by the end of 1979.

This rapid growth of hospice care necessitates close scrutiny by third-party payers. Thus, the purpose of this statement is to examine several key aspects of the growth, delivery and financing of hospice care and to delineate the position of the Blue Cross and Blue Shield organizations regarding these issues. Because the experience of Blue Cross and Blue Shield Plans with hospice care is still limited, this statement should be viewed as a preliminary position that will evolve into more permanent policy as the development, cost, utilization and quality of hospice services are studied and evaluated further.

### HOSPICE CARE

Hospice care is an integrated set of services designed to provide palliative and supportive care to terminally ill patients and their families. Its goal is to enable dying persons to live their remaining lives at home or i ;ome other comfortable setting around their families, friends and important possessions, as free as possible from the pain and other symptoms of terminal illness and the fear of their recurrence. While the hospice concept is not new, current interest in it stems from the fact that much of the care now available to dying persons is viewed as insensitive or inconsistent with the physical, emotional, social and spiritual needs of many terminally ill persons and their families.

Hospice care is therefore offered as a medical alternative to traditional forms of medical and nursing care. A major focus of hospice care is the relief and control of pain or the physical or psychological symptoms associated with many terminal illnesses. This may require round-the-clock attention and hence 24-hour patient access to nursing and physician services. Equally important is the availability of a comprehensive range of support services designed to help both patient and family cope with the stress, trauma and exhaustion that usually accompany terminal illness. Key among these are personal counseling for patient and family members, help with housekeeping chores and other duties, and hospice staff visits or other contact with family members for a period after the patient's death.

Hospice care is provided in a number of settings, including the home, hospital, nursing home and freestanding hospice facility. While there are advantages and disadvantages to each setting, the critical factor seems to be a comfortable, flexible environment conducive to interaction among a patient, his family, friends and health care providers. Because hospice care involves relatively low medical technology, elaborate medical facilities are not of paramount importance. Consequently, the

home is the preferred setting for hospice care, except where case management requires a more controlled, inpatient environment. This means that even where the major emphasis of hospice care is on providing services in the home, formal arrangements for using appropriate inpatient facilities are quite important. Without such arrangements, high quality care may be jeopardized, and the continuity between hospice care in the home and in the hospital or other facility may be difficult to maintain.

## ISSUES

It is not yet clear what types of hospice care are most appropriate nor how they might best be organized, administered and funded. Even so, hospice care is being provided in many places throughout the country. There are few established programs, although there are many demonstrations and other programs in their early phases. Indeed many health care providers and community groups have already approached Blue Cross and Blue Shield Plans to ask for reimbursement for hospice services. The results of this contact have varied; yet the issues raised in each instance have striking similarities.

### *Quality*

The quality of hospice care is the first and most important issue. Evidence from various studies concerning care of the terminally ill suggest that hospice care can be effective not only in reducing pain and increasing patient comfort but in relieving many of the anxieties and other problems experienced by these patients and their families. These studies, however, involved patients treated in established health care programs, including hospice programs recognized for the skill and conscientiousness of their staff and the professionalism and sensitivity exercised in designing and delivering patient care. Far less is known about other hospice programs and the nature and quality of their patient and family care. In the United States, moreover, there are no generally recognized standards for evaluating this care. As a result, support of hospice programs by third-party payers, in particular, and the public, in general, needs to be exercised cautiously, or not at all, until there are generally recognized professional standards defining when and under what conditions hospice care is medically appropriate, what constitutes a program of hospice care, and who can provide such care and in which settings.

### *Models of hospice care*

There are several models of hospice care, and deciding which ones deserve financial support raises significant questions. Because local circumstances vary, hospice care will be provided primarily in the home care setting in some communities and primarily in a hospital, nursing home, or other setting in others. From a cost as well as a quality standpoint, the preferred model of hospice care appears to be the one based in a sound home health care program. Models emphasizing inpatient care may be less desirable for most patients and families, especially from a cost standpoint. Certainly wherever inpatient hospice care is offered, existing inpatient facilities should be used, where possible, not only because of the additional costs involved in constructing and operating freestanding hospice facilities, but also because the use of such facilities can encourage greater integration of the hospice concept into the overall health care delivery system. A model utilizing a freestanding hospice facility appears nonetheless to be attractive to many hospice organizers, partly because it presumably permits hospice services to be developed and delivered relatively free of major confrontations with traditional health care providers.

These different perspectives pose some difficult problems for health planners, third-party payers, and providers alike. To resolve them, community need for hospice care must be measured and the efficiency and effectiveness of alternative care settings must be evaluated. Moreover, hospice care organizers will have to work closely with other health care providers, planners and financing organizations to assure efficient integration with and use of existing health care resources.

### *Cost*

There is not sufficient evidence or experience to be able to state conclusively whether hospice care is more or less costly than alternate modes of health care. While some have claimed that hospice care can contain costs associated with caring for the terminally ill, hospice care may, in fact, yield no significant savings when compared to the costs of caring for terminally ill patients in traditional acute care or nursing home settings. Indeed, terminally ill patients often receive relatively few services in traditional care settings, since therapeutic or curative measures may have proven unsuccessful and been discontinued. This must be contrasted with the

broad nature of medical and social services, the highly professional staffing patterns, and the specialized staff skills and training levels of well structured hospice programs, all of which may produce costs as great as those in general hospitals. However, even if hospice care does prove to cost less than care in an acute care or other setting, its availability alone may generate new service demand and, consequently, new costs. Therefore, the need for both providers and payers to develop measures to contain the cost and to control the utilization of hospice services is imperative, especially if such services are to be provided within the financial constraints of insurance contracts and the fiscal constraints of government budgets.

*Benefit coverage*

It is unclear to what extent Blue Cross and Blue Shield Plans and their subscribers should or are willing to cover the full range of medical and social services provided in a comprehensive program of hospice care. Certain aspects of hospice care are already covered under many existing subscriber contracts. Other services are not covered, however, and many of these are considered by hospice advocates to be essential to the hospice concept and its effectiveness. Round-the-clock service availability, a patient's family's need for an extensive range of social and homemaker service, bereavement visits and the administration of medication by family members are some examples. Barriers are also posed by many existing benefit restrictions such as homebound criteria and prior hospitalization requirements. The appropriateness and duration of hospice care involve equally important questions, the resolution of which, along with these other questions, must evolve from thorough evaluation of hospice care programs and limited experiments with insurance coverage for hospice services not covered under existing benefit arrangements.

*Reimbursement*

There are few precedents for addressing the reimbursement of hospice services. Major concerns that need to be studied and considered in determining the terms and methods for reimbursing any health care service are assuring equity among providers of like services, meeting financial requirements, establishing incentives that encourage sound financial management and appropriate utilization and providing for adequate records. Therefore, specific payment arrangements for hospice care should be viewed as tentative until experiments with different payment arrangements such as prospective rates or case-based payments can be evaluated.

POSITION

The Blue Cross and Blue Shield organizations support the basic ideas, concepts and philosophy of hospice care. Hospice care is a major innovation in the delivery of humane and compassionate health care to the terminally ill and their families, and if properly implemented, can provide a medically, psychologically, socially and spiritually sound alternative to the traditional forms of health care. The Blue Cross and Blue Shield organizations have a responsibility as major payers of health care to contribute to the sound development of hospice care services in the communities they serve.

*Overall criteria*

General support by Blue Cross and Blue Shield Plans of hospice care services and programs should be based on several criteria:

There must be demonstrated community need for these services or programs.

There must be assurances that the care provided meets medically acceptable standards of quality and sound principles of health care administration.

There must be assurances that the delivery of hospice care is performed in an efficient and economical manner and physical setting that make effective use of existing community resources.

*Programmatic conditions*

Actual financial support by Blue Cross and Blue Shield Plans of specific hospice services or a specific program of hospice care should consider the following programmatic conditions:

(1) Hospice care should consist of a coordinated program of home health and inpatient services provided by an interdisciplinary team directed by a qualified licensed physician and centrally coordinated by a qualified registered nurse.

(2) Hospice care services should be made available to terminally ill patients and their families only on the basis of written, well-defined criteria that address a patient's medical condition and prognosis and the state of the patient's home and family conditions.

(3) Hospice services should be provided by or under the auspices of a duly licensed home care program, hospital, or nursing home with suitable arrangements for making available alternate levels of care that may be necessary.

(4) A program of hospice care should include the utilization of well-trained lay and professional volunteers.

(5) Providers of hospice services must have or establish guidelines and mechanisms for determining the necessity and appropriateness of hospice care.

(6) A program of hospice care should comply, or eventually comply, with all applicable local and state health planning requirements. Among these requirements should be a determination of community need for hospice services and a determination of the appropriateness of any new facilities in light of existing bed capacity and its alternative uses.

(7) Hospice services and any program of hospice care must meet accreditation requirements eventually developed for the delivery of hospice care and administered by a recognized, national accreditation organization.

*Payment principles*

Payment by Blue Cross and Blue Shield Plans for hospice services should be based on the following principles:

(1) Initial payment arrangements for hospice services should be made on a pilot or demonstration basis with a limited number of providers. These arrangements should take the form of formal agreements that specify payment terms and financial and statistical record keeping requirements and provide for strict cost containment and utilization controls and thorough evaluation of service delivery and its financing.

(2) Payments for services should, to the extent possible, be made under existing benefit provisions or modifications to them. Any benefit modifications or new benefits to cover hospice services should be tried on a pilot or demonstration basis with a limited number of accounts or subscribers.

(3) Payments should be made only for patients who meet written, detailed definitions of benefit eligibility.

(4) Payments should be made only for hospice services that have specified purpose and scope.

(5) There should be limits on Plan and subscriber liability. Hospice services should be medically necessary and appropriate and be provided over a reasonable duration of time. Reimbursement for hospice services should not be available for open-ended time periods.

(6) Both benefit and payment terms covering hospice care should provide incentives that encourage delivery and use of the most economical and efficient hospice service practicable.

(7) Payments for a total care program of hospice services generally should not exceed payments for a total care program of acute inpatient services what would be available and medically appropriate for the same patient.

## STATEMENT OF WILLIS B. GOLDBECK, EXECUTIVE DIRECTOR, WASHINGTON BUSINESS GROUP ON HEALTH

Mr. GOLDBECK. Mr. Chairman, I am Willis Goldbeck, Director of the Washington Business Group on Health, a major employer organization. We support H.R. 5180 because it passes every medical, economic, and moral test. We have heard and considered the six counterarguments, one being that hospice is an unproven concept. This is simply not true. It is very old and very proven.

When the bottom line oriented firms like General Electric add a hospice benefit, or actuaries at Equitable decide that hospice coverage is so cost effective it can be added at no premium increase, the question of the concept's validity should be considered moot.

The second argument, the HCFA position, is that the concept is fine but let's wait for further studies. This in my view has no merit. The concept is not just OK, it is indeed proven. There are more than enough private sector studies and demonstrations to give you the data upon which to make rationale decisions without further equivocation.

If there is new and better information to be forthcoming from other studies now under way, and in the future, let them find their way into the proper regulatory process, the proper implementation process, just as is the case with every other piece of legislation that can be studied at any time, and modified, after passage.

Third, the contention that hospice reimbursement would lead to more unnecessary and expensive facilities. Again, we do not believe this is correct. The bill does and must emphasize that hospice is a program, not a place. It is primarily a home care program. Hospitals will in fact lose revenues due to the transfer of the terminally ill from acute care beds to hospice care. That is appropriate. You must not allow this to be described as a problem. Nor should any hospital based hospice program be allowed to carry any of the operating costs of the nonhospice elements of the hospital.

The fourth argument is that there are not sufficient standards to assure quality in hospice. We believe this is wrong. The work done by the hospices themselves, the National Hospice Organization, the quality standards being designed by JCAH in the Kellogg Foundation study, all provide ample protection.

The ultimate test of hospice is the acceptance by the dying and their families. The care is more appropriate for them in the hospice setting.

Fifth, some question why medicare, even private insurance, should pay for respite or bereavement care for the family. This attitude is a demonstration of lack of knowledge of the pressures on families, or the health and economic value of the family and friends as care providers.

In crass terms, insurance should be reimbursed for those services because they are cost effective and improve the quality of care.

The sixth question is whether or not we can be sure this new benefit will not be abused. Let me respond to that question with one of my own. How many people do you think will volunteer to become terminally ill to take advantage of these benefits? If there is abuse, it will be by providers, and not by the terminally ill. The way to correct this problem is to punish the perpetrators, not deprive the patients.

In closing, hospice and this legislation respects the dignity of dying, the humanity of caring, the art of medicine and the rights of the individuals. Hospice is cost effective at a time when the public and private sectors have really no choice but to seize every opportunity for cost-effective programs. Hospice recognizes the value and participation of family and friends. Hospice honors the value, in health as well as economic terms, of volunteers.

H.R. 5180 does not propose radical new programs. Rather, it seeks to correct an economic disincentive for the use of appropriate and needed medical and health care services. This is an opportunity for leadership, for the Congress, and for those who support this legislation.

Most of hospice care patients are dying from cancer. Last week we lost one opportunity for leadership to prevent cancer as the administration caved in to the tobacco industry. Today, you have the opportunity to at least make some progress toward assisting cancer victims by suporting H.R. 5180. We support this bill because it is good—good for the terminally ill, good for their families, good for

quality of care, good for our business constituents, and good for the country. That seems to be reason enough.

Thank you very much.

Mr. RANGEL. Thank you.

Mr. Neiswanger.

## STATEMENT OF ROBERT M. NEISWANGER, SECRETARY, GROUP DEPARTMENT, TRAVELERS INSURANCE CO.

Mr. NEISWANGER. Thank you. I am Robert Neiswanger. I am a Secretary of The Travelers Insurance Co., One Tower Square, Hartford, Conn. 06115. The Travelers is one of the largest underwriters and administrators of group health insurance programs. We currently have programs with over 47,000 employers and cover over 10 million individuals. My duties at The Travelers involve cost containment and product design.

I appreciate the opportunity to speak before you today and will confine my remarks to the issue of hospice benefits under group insurance programs because that may be of interest in your deliberation as to the inclusion of hospice services under medicare.

We are interested in Hopice for a variety of reasons. First, from the humane or social side of providing assistance to individuals and their families in perhaps the most difficult crisis any of us have to face. Second, because hospice care may be an alternative to hospital confinement and so has the potential to help contain the cost of health care.

If we want to see a time when general hospitals are used only for patients in need of acute curative care, then we must encourage alternatives for other patients whose needs are specialized and that can be met in a less costly setting. Finally, as a major underwriter of group insurance plans we want to be in the forefront of offering the latest in benefit design to purchasers of group health programs.

A few of our large group policyholders have added hospice benefits to their group program. At present, there is no dominant pattern as to the benefit design. For example, some employers have added hospice services as a basic benefit reimbursing 100 percent of the reasonable charges.

Other employers have decided to add hospice services to more the broad list of covered benefits under major medical type programs. For some, that is a natural approach because most major medical programs already cover some services that could be provided to the patient confined at home. For example, in addition to the services of a physician, major medical covers nurses and home health aides. Major medical also covers prescription drugs, medical supplies, and physiotherapy, all of which are important to the patient who can be treated at home.

At least one large employer has added hospice benefits but decided not to include the bereavement service. The diversification for benefit design for large employers is not surprising because major corporations often tailor make their group health benefits. While large employers have flexibility in plan design and have no difficulty in adding hospice benefits, small employers select their programs from among several standard packages of benefits.

We believe that many of these smaller employers will also be interested in a hospice benefit particularly as the movement grows and insurance benefits are included in the program of major corporations. Therefore, in the next few months, we hope to announce a new standard package of group benefits that will include hospice service. This package will be offered to employers with as few as two employees.

Briefly, the program will cover home health care services, including family counseling by social workers or pastoral counselors. Covered services will also include room and board and ancillary medical services if a hospice provides a free-standing facility as well as the home-care program. Finally, the benefit will cover bereavement counseling for the patient's immediate family for a limited period following the patient's death.

It seems clear that as community hospice agencies grow and establish themselves as organizations that provide compassionate quality services to the terminally ill, employers and employees will seek group insurance benefits to cover these services. The Travelers, and probably other major underwriters, anticipate this growth and we are prepared to offer hospice benefits to meet the needs of the group insurance marketplace.

Again, let me thank you for the opportunity to speak on behalf of The Travelers Insurance Co.

Mr. RANGEL. Congratulations to Travelers.

## STATEMENT OF RONALD E. ZIER, VICE PRESIDENT OF PUBLIC AFFAIRS, WARNER-LAMBERT CO.

Mr. ZIER. Mr. Chairman, I am Ronald Zier, vice president of Warner-Lambert Co. I am here in support of 5180 in terms of the humanity, dignity, and economy that the resolution suggests.

I would like to look at H.R. 5180 from two perspectives. One, as a major corporation providing health benefits for its employees, retirees, and their dependents, a health program that costs us $24 million a year. Second, I would like to address the issue from the point of view of a corporation that has had 5 years experience working with the professionals throughout the country who are involved with the hospice programs.

In many ways, we see that there is a paradox in terms of present medicare coverage. It is not that there is not enough money or enough people or enough equipment within the medicare program. The irony it seems to us is that there may be too much. Because of the reimbursement coverage that has been mentioned here several times this morning, medicare seems to favor the high cost, high technology care-oriented therapies which are often ineffective and frankly inappropriate in treating terminal patients.

At the same time, as has been suggested here as well this morning, medicare does not allow the option of going the hospice way, an alternative that not only offers the patient and his family a better way, but a more dignified way to deal with the terminal condition.

Effective January 1, 1982, Warner-Lambert has attempted to address this issue for its 80,000 employees, retirees, and their depend-

ents, by amending our benefit program to offer hospice care for that group.

In that sense, we have joined with General Electric and other members of the Fortune 500 in offering this option.

Frankly, when we learned that hospice legislation would be considered by Congress, Warner-Lambert, through its foundation, commissioned an independent analysis of the fiscal impact of H.R. 5180 on the medicare trust fund. That study was conducted by Health Policy Alternatives, Inc., here in Washington.

We respectfully submit that report for the record and ask that it be included as part of the testimony.

Mr. RANGEL. Without objection.

[The analysis follows:]

HEALTH POLICY ALTERNATIVES, INC.—A SUMMARY AND STATEMENT OF CONCLUSIONS OF COST AND FISCAL IMPACT ANALYSIS OF PROPOSED NATIONAL HOSPICE REIMBURSEMENT BILL TO BE INTRODUCED BY CONGRESSMAN LEON PANETTA ET AL., FIRST SESSION OF THE 97TH, CONGRESS, COMMISSIONED BY THE WARNER-LAMBERT FOUNDATION, NOVEMBER 1981

Health Policy Alternatives, Inc. is a Washington, D.C. organization for the study of health care costs and delivery mechanisms.

William D. Fullerton, principal officer, is former deputy administrator of the Health Care Financing Administration and served for six years as chief of the professional health staff of the Committee on Ways and Means, U.S. House of Representatives, and, later, as Washington head of the American Association of Foundations for Medical Care and American Association of the Professional Standards Review Organizations.

Irwin Wolkstein, principal officer, served as deputy director of the Medicare program in charge of program policy, director of the Social Security system's legislative activities in regard to health insurance, and associate director of the Washington office, American Hospital Association. He is the senior author of this report.

Michael M. Hash, principal officer, has served as director, division of legislation, American Hospital Association; and associate director, Washington office, American Hospital Association.

Daniel I. Zwick, special consultant, is former associate adminsitrator for planning, evaluation, and legislation of the United States Public Health Service.

SUMMARY OF COST ANALYSIS OF HOSPICE REIMBURSEMENT BILL

Hospice care is a comprehensive program of home care and inpatient services designed to improve the quality of life for terminally ill persons and their families. It emphasizes reduction in their pain and suffering, primarily at home, rather than the pursuit of ineffective and costly treatment in the hospital. At the present time, hospice services—as such—are not a benefit covered by Medicare, although more expensive alternative forms of treatment of terminally ill Medicare-eligible patients are reimbursed, no matter what their efficacy, as are some of the individual services required by hospice patients.

The hospice bill would add hospice services as a covered benefit under Part A of Medicare. The bill would allow reimbursement for hospice services provided by a participating hospice to a patient whose life expectancy is certified to be six months or less. In order to participate, a hospice would have to provide both home health and inpatient services on a seven-day-a-week, 24-hour-a-day basis and would have to employ a team of hospice professionals including physicians, registered nurses, social workers, and volunteers.

This paper examines available data on the potential costs of the proposed legislation and concludes that the coverage of comprehensive hospice services may be added to Medicare as proposed by the hospice bill, without increasing the costs of the Medicare program. In fact, the study indicates that the proposed legislation probably would result in substantial aggregate dollar savings.

Key findings of the cost study are:

Approximately 12,000 Medicare-eligible patients are estimated to be receiving in 1981 the kind of hospice services proposed to be covered. The number of patients likely to use hospice services would grow to some 60,000 by 2,000, as hospice costs

are covered, availability of the service increases, and acceptance of the hospice concept by physicians rises.

All of the existing studies of hospice care have reported that the average incremental costs of hospice care have been offset by reductions in the average costs of currently covered Medicare services to the terminally ill. None has reported net increases in costs.

Potential savings arise from reductions in the number of days of hospital care and reductions in the use of expensive services during hospitalization.

An average day of hospice care of all types tends to be one-fourth to one-fifth the average cost of hospital care for cancer patients. The average period of care in a hospice tends to be 40–50 days, and we estimate that use of hospice services pays for all hospice costs—not just added costs—if it reduces the average use of hospital care by 8 to 10 days per patient. At least this level of reduction in hospital use—or more—has been achieved by all existing hospice programs that have reported this kind of data.

Potential cost savings for this bill are estimated at between $13 million and $50 million the first year, rising to between $30 million and $130 million the fifth year.

To ensure that Medicare payments for hospice care would not exceed anticipated amounts, the proposed bill would limit average payments for hospice care to a hospice program to an amount equal to 75 percent of the average cost of six months of terminal care for non-hospice cancer patients covered by Medicare in the area. In addition, the bill includes a number of other important limitations on the number of eligible patients and the number of days of eligibility. The price of services would be limited by the reasonable costs and charges rules of present law.

### COST ANALYSIS OF PROPOSED HOSPICE REIMBURSEMENT BILL

This paper examines available data on the potential costs of proposed legislation to add hospice services as a covered benefit under Part A of Medicare. The study concludes that adding coverage of comprehensive hospice services, as proposed, would likely result in substantial aggregate dollar savings to the Medicare program.

*Available information on costs*

The potential costs of providing hospice benefits to Medicare beneficiaries depend on a number of factors:

The number of beneficiaries who would be eligible for the new benefits,

The number of eligible beneficiaries who would use such benefits, initially and over the long term,

The nature of the newly covered hospice services, and

The average costs of added hospice services compared to the costs of other covered Medicare services that would be foregone.

Information is available on all of these four factors. In some cases, the available information is limited due to the short time some hospice programs have been in operation and to gaps in the reported data. In other cases, the analysis of available information is complicated by the great diversity in the nature of the hospice programs that have developed around the country in the last few years. Many of the existing hospice programs do not now provide the comprehensive range of hospice services that are required in the proposed bill.

A scientific study in which an experimental group is given access to reimbursed hospice care over a period of years (to allow for growth in acceptance of the service by physicians and patients), and a perfectly matched control group is denied access to hospice services seems extremely difficult to carry out, so that a precise measure of exact differences resulting from enactment of hospice coverage by Medicare will probably not become available. What can be done is to make intelligent use of the imperfect information that can be obtained. Because the data indicate that in no case that has been observed has there been an increase in cost when hospice care was covered, the data imperfections do not impede reaching the conclusion that no added cost would occur. They only create difficulty in determining the amount of the potential saving.

This paper reviews the information available on the four factors listed above. This information is based on studies and reports on hospice care accumulated over the last few years, including some completed very recently. The principal sources of information are listed in Appendix A to this paper. Additional data will be developed in future months from on-going studies sponsored by the Blue Cross and Blue Shield

Associations, the Health Care Financing Administration (HCFA),[1] and other parties.

However, none of these studies will provide the definitive results of a perfectly designed experiment with an exposed population and a control group,[2] so that most of the gaps in present data with regard to the precise cost differences resulting from coverage of hospice care compared with current coverage will remain. The direction of past studies on cost differences—saving or a "wash"—can be expected to be reported by the new findings.

*Number of eligible beneficiaries*

Since the literature (see Appendix B) suggests that at least 90 percent of patients receiving care in hospice programs are cancer patients and their families, it is possible to estimate the number of potential beneficiaries of the Medicare hospice benefit using available data on cancer deaths. As set our in detail below, we calculate that some 270,000 Medicare eligible patients would meet the "terminal illness" condition for hospice services in 1981, a number which would rise to approximately 310,000 by the year 2000.

As indicated in Table 1, the number of cancer deaths in the United States exceeded 400,000 in 1980. It has been estimated (in a study sponsored by the National Institutes of Health at the Public Services Laboratory of Georgetown University) that the number of cancer deaths will approximate 467,000 in the year 2000.

Approximately 60 percent of cancer deaths occur among persons 65 years of age or older. As noted in Table 1, this ratio has been increasing slowly, but steadily, in recent years. It is estimated that in 1981 there will be about 264,000 deaths from cancer among persons 65 years and older, and by 2000 there may be over 300,000 deaths from cancer in this age group.

A National Cancer Institute survey found that over 93 percent of cancer patients over the age of 65 were Medicare beneficiaries and that about 1 percent of cancer patients uner 65 years of age were Medicare beneficiaries. As detailed in Appendix B, less than 10 percent of hospice patients historically have been noncancer patients. Adding 10 percent of the number of cancer patients as a conservative estimate of the number of noncancer patients eligible for hospice services, Table 2 presents estimates of the total number of Medicare beneficiaries that would meet the terminal illness criterion for eligibility for hospice services under the proposed bill. The current HCFA study does not develop new data on this issue. For eligibility for hospice services under the proposed bill, a number which will grow from 272,000 in 1981 to 309,000 in 2000. The current HCFA study does not develop new data on this issue.

TABLE 1.—CANCER MORTALITY

| | Total | Under 65 | Over 65 | Percent over 65—total |
|---|---|---|---|---|
| Year: | | | | |
| 1975 [1] | 365,677 | 150,364 | 215,313 | 58.7 |
| 1976 [1] | 377,280 | 152,737 | 224,543 | 59.4 |
| 1977 [1] | 386,649 | 154,424 | 232,225 | 60.1 |
| 1978 [1] | 396,939 | 155,797 | 241,142 | 60.8 |
| 1979 [2] | 395,000 | 152,000 | 243,000 | 61.5 |
| 1980 [2] | 405,000 | 154,000 | 251,000 | 52.1 |
| 1981 [2] | 420,000 | 156,000 | 264,000 | 62.8 |

[1] National Center for Health Statistics.
[2] The totals for these years are estimated by the American Cancer Society—the distribution by age is based on past trends.

[1] The HCFA demonstration project, the results of which will not be published before late 1983, will compare costs of traditional care at "comparison sites" with costs of hospice care. One group of hospices in the study is receiving Medicare reimbursement under waivers of the rules, while a second group has not received such waivers.

Since the comparison group receiving traditional care and the experimental groups receiving hospice care will not necessarily be selected from similar populations, no manipulation of the data after the fact will transform the results of the demonstration project into the sort of reliable statistics that would be generated by random sampling of the same population to establish a true comparison. Furthermore, the study will not provide data on the portion of the population that would obtain hospice services, and the duration of the study may not be sufficiently long to provide a basis for reliable prediction of long-term changes in the use of hospice care.

[2] A study being conducted at the Veterans Administration's Wadsworth Hospital in California does include a control group of volunteer patients. Data collection in that study has just begun.

TABLE 2.—ESTIMATES OF POTENTIAL NUMBER OF MEDICARE ELIGIBLES FOR HOSPICE CARE

| | Estimate of cancer deaths [1] | | Medicare cancer patients [2] | Potential other patients [3] | Potential total eligibles |
|---|---|---|---|---|---|
| | Under 65 | Over 65 | | | |
| Year: | | | | | |
| 1981 | 156,000 | 264,000 | 247,000 | 25,000 | 272,000 |
| 1985 | 158,000 | 271,000 | 254,000 | 25,000 | 279,000 |
| 1990 | 161,000 | 280,000 | 262,000 | 26,000 | 289,000 |
| 1995 | 164,000 | 290,000 | 271,000 | 27,000 | 298,000 |
| 2000 | 167,000 | 300,000 | 281,000 | 28,000 | 309,000 |

[1] Estimates by American Cancer Society and Georgetown University's Public Services Laboratory.
[2] Assumes 93 percent of cancer patients over age 65 and 1 percent of cancer patients under age 65 are Medicare beneficiaries.
[3] Assumes noncancer hospice patients would be about 10 percent of cancer patients.

*Number of beneficiaries likely to use hospice services*

The number of eligible Medicare beneficiaries that are likely to desire and be acceptable for hospice care benefits, initially and ultimately, depends upon a number of considerations:

Acceptance of hospice care among terminally ill persons and their families;

Acceptance of hospice by oncologists and other practicing physicians who are responsible for the care of cancer patients and other potential hospice users;

Availability of hospice care services in various parts of the country; and

Acceptance of the patients by a hospice because the patient is willing to forego curative services, and has been certified to be terminally ill.

The acceptance and availability of hospice services have been increasing progressively throughout the country, as documented by a series of recent reports on the rapid growth of hospice care programs in the United States. A survey by the General Accounting Office in 1978 identified 59 operating hospice care programs and 73 others in the process of establishment. In 1979, the directory of the National Hospice Organization listed about 210 programs. By June of 1981, a report of the Joint Commission on the Accreditation of Hospitals identified 440 operational programs and indicated that about 350 additional programs were known to be under development.

Nevertheless, these types of services are still not available to many prospective patients and their physicians. It has been estimated that between 40,000 and 50,000 patients and their families are receiving some form of hospice care in the United States at the present time, and less than half that number may be receiving a comprehensive set of hospice inpatient and home care services along the lines required to be provided by the proposed bill.

These numbers are supported by the above-mentioned Joint Commission study, which reports and average caseload of 16 patients among the programs identified. Because the average duration of hospice care is relatively brief—about 50 days—this study would indicate an average annual caseload per program of more than 100 patients. The total national caseload thus will likely exceed 45,000 patients in 1981.

An in-depth study of 24 hospice care programs in 1980 by the University of Arizona College of Business and Public Administration (funded by the Department of Health and Human Services) found that about 42 percent of the programs provided a comprehensive range of services, including inpatient, home care and bereavement services. This group of 24 programs tended to be larger than the Joint Commission averages, serving an average of 167 patients annually. The average length of stay of patients in these programs was 47 days.

These data suggest that about 20,000 of the current hospice patients may be in programs with comprehensive services. If about 60 percent of these patients are 65 years or older (the percent of cancer deaths that are among persons over age 65), then as many as 12,000 Medicare beneficiaries are in comprehensive hospice care programs at the present time.

A number of agencies studying hospice care activities have estimated the percentage of terminal cancer patients who would likely desire and be accepted for hospice care in the long run. The percentage represents the number who have been identified as terminally ill sometime before death, who have forgone attempts at curative or life-extending care, who have a person able to act as care giver at home, and who have access to hospice care. These estimates, which are set forth in Table 3, range

from 10 percent to 40 percent of terminal cancer patients. A middle-range estimate for home-care oriented hospice services would appear to be in the 15 to 25 percent range, taking into account that some communities may never have hospice services readily available. The current HCFA study does not develop new data on this issue.

Table 4 presents estimates of the potential users of hospice care among Medicare beneficiaries through the year 2000. Low (10 percent), moderate (20 percent) and high (40 percent) estimates are presented. The percentages are portions of Medicare eligibles (from Table 2) assumed to use hospice care. Using the middle estimate, we forecast use of hospice care by some 62,000 Medicare beneficiaries annually by 2000. We estimate that if hospice benefits had been provided by Medicare when it was first enacted, about 54,000 Medicare beneficiaries would be receiving comprehensive hospice care this year compared with 12,000 at present.

TABLE 3.—*Estimate of potential use of hospice care by cancer patients*

| Source: | *Percent* |
|---|---|
| Virginia Department of Health | 10–15 |
| Cleveland Health System Agency | 25 |
| Marin County, Calif | 28 |
| Western Center for Health Planning | 30–35 |
| Jacksonville, Fla | 34 |
| Kaiser-Permanente Medical Center, Hayward, Calif. (primarily inpatient hospice care) | 85 |

TABLE 4.—ESTIMATES OF POTENTIAL MEDICARE USERS OF HOSPICE CARE

| | Low estimate—10 percent | Medium estimate—20 percent | High estimate—40 percent |
|---|---|---|---|
| Year: | | | |
| 1981 | 27,000 | 54,000 | 108,000 |
| 1985 | 28,000 | 56,000 | 112,000 |
| 1990 | 29,000 | 58,000 | 116,000 |
| 1995 | 30,000 | 60,000 | 120,000 |
| 2000 | 31,000 | 62,000 | 124,000 |

Note: Percentages are proportions of potential Medicare eligibles (Table 2) assumed to use hospice care.

Of course, even after Medicare coverage is enacted, the potential patient load will only be achieved over time, as there is more widespread acceptance and availability of hospice care. Many of the existing limited hospice programs would probably expand relatively quickly to more comprehensive programs. The development of programs in rural and inner-city areas would be likely to take longer. Table 5 presents estimates of potential schedules of build-up, assuming the moderate and high estimates of long-term potential use, beginning from the base indicated by the this year's JCAH survey and grading in to ultimate potential participation estimates.

*Nature of newly covered services*

The scope of the newly covered services is a third factor that will determine the potential costs of extending Medicare coverage to hospice care. The incremental impact will be based on the differences in benefits between the current scope of coverage under the Medicare program and those services needed for effective hospice care programs.

Most of the services called for in a comprehensive hospice care program are already covered under the Medicare program. Table 6 compares the proposed hospice care benefits and existing benefits. While hospice care involves changes in the nature of an relationships among certain services, such as inpatient care and home care, it does not involve the addition of a substantial number of expensive new services.

TABLE 5.—ESTIMATES OF POTENTIAL RATE OF BUILDUP TO POTENTIAL

| | Medium estimate | | High estimate | |
|---|---|---|---|---|
| | Potential | Buildup | Potential | Buildup |
| Year: | | | | |
| 1981 | 54,000 | 12,000 | 108,000 | 12,000 |
| 1985 | 56,000 | 35,000 | 112,000 | 55,000 |
| 1990 | 58,000 | 45,000 | 116,000 | 85,000 |
| 1995 | 60,000 | 53,000 | 120,000 | 103,000 |
| 2000 | 62,000 | 60,000 | 124,000 | 120,000 |

TABLE 6.—COVERAGE OF HOSPICE SERVICES UNDER CURRENT MEDICARE BENEFITS

| | Now covered | Not covered |
|---|---|---|
| Home care: | | |
| Physician services | X | |
| Nursing visits | X | |
| Personal care | | |
| Homemaker care | | X |
| Consultation services | | X |
| Respite care | | X |
| Bereavement support | | X |
| Inpatient: | | |
| Room and board | X | |
| Laboratory and radiology | X | |
| Pharmacy | X | |
| Physical therapy | X | |
| Chaplain | X | |
| Medical social services | X | |
| Physician services | X | |
| Respite care | | X |
| Transportation | | X |
| Bereavement support | | X |

Source: National Hospice Organization, "Delivery and Payment of Hospice Services: Investigative Study," September 1979.

Even when provided in a inpatient setting, the added hospice services tend to be simpler and less expensive than the inpatient hospital services they replace. As discussed below, even a small reduction in the use use of hospital services would more than offset the costs of the new services that are authorized as part of the hospice care benefit.

The provision of a comprehensive package or services is required by the proposed bill in order to maximize the potential for substituting lower cost services for intensive inpatient hospital care, whether the patient requires home care, nursing-home-type services or inpatient hospital services. If inpatient care is required during periods of acute illness, the hospice would limit the use of expensive laboratory services, chemotherapy and similar services.

*Cost comparisons*

The cost of hospice care services compared to the costs of currently covered Medicare benefits provided to terminally ill patients might result in one of the following conditions:

1. The average costs of hospice care might be less than the foregone services;
2. The average costs of hospice care might be essentially the same as the foregone services, or
3. The average cost of hospice care might be more than the foregone services.

All of the studies and analyses to date have reported that the costs of hospice care are less than the costs of traditional care of terminally ill cancer patients. The existing studies also report that introduction of hospice care results in substitution of less-expensive hospice care for acute inpatient care.

Each of the above-mentioned elements is discussed below. First, we set out the reported costs to Medicare of traditional care of teminally ill cancer patients. These costs are them compared with the reported average costs of hospice care. Finally, we

discuss those studies which have focused on the extent to which users of hospice care forego more expensive care. All such analyses conclude that costs for a significant number of additional inpatient hospital days would have been incurred by the average study participant in the absence of hospice care.

There are several studies which report the average costs to Medicare of caring for terminally ill cancer patients in the traditional manner. For example, an anslysis by the National Center for Health Statistics, based on Medicare costs data, computed the average Medicare payments for hospital care for approximately 100,000 cancer patients who died in a hospital. The costs are the total for the calendar year in which death occurred and amounted to over $4,100 in 1976. As a statistical matter, this amount represents costs for, on the average, a 6-month period (Table 7). The comparable 1980 amount, simply adjusted for inflation in hospital costs between 1976 and 1980, would be about $6,000.

Preliminary data from a recent analysis by the Health Care Financing Administration, reviewing 1976 data for Mecicare patients, indicate that the costs of care for deceased Medicare patients was about $3,700 during the last twelve months of life. On an inflation-adjusted basis, the 1980 figure would be about $5,700. The comparable costs for deceased cancer patients during the last twelve months of life, according to the preliminary data, were about $6,300 in 1976; adjusted for inflation, the 1980 figure would be about $9,000. A comparison of the two studies of Medicare data suggests that two-thirds of the costs for the last 12 months of life of a terminally ill patient are incurred in the last 6 months of life.

In comparision, a recently reported study sponsored by the National Cancer Institute of the costs of caring for cancer patients in three comprehensive hospice programs in 1980 indicated a mean cost of $3,660 per patient. Average costs varied among the three programs as follows:

| | |
|---|---|
| Hillhaven Hospice, Tucson, Ariz. | $3,204 |
| Kaiser-Permanente Hospice, Los Angeles, Calif. | 4,554 |
| Riverdale Hospice, Boonton, N.J. | 3,223 |

A report in 1981 by the Blue Cross and Blue Shield Associations concludes that "although none of the Plans have experienced enough utilization to derive definitive conclusions about the cost of hospice care, costs generally appeared lower for hospice care than for acute inpatient care." The report was based on a 1980 survey of 12 plans that have begun paying for hospice services.

TABLE 7.—AVERAGE MEDICARE REIMBURSEMENT FOR HOSPITAL CARE DURING YEAR OF DEATH FOR PERSONS DYING IN THE HOSPITAL

| | 1974 [1] | 1975 [1] | 1976 [1] | 1980 estimates [2] |
|---|---|---|---|---|
| All case | $2,110 | $2,590 | $3,069 | $4,432 |
| Cancer cases | 2,789 | 3,453 | 4,142 | 5,981 |

[1] Date for 1974, 1975 and 1976 are from the Health Care Financing Administration.
[2] Estimate is based on the increase in hospital costs between 1976 and 1980 due to inflation. Other increases in costs due to new methods of cancer treatment are not reflected.

Comments from Blue Cross-Blue Shield personnel suggest that no strong pressure has been felt to conduct cost studies because the number of potential users of hospice care is relatively small. Nevertheless, some of the Plans surveyed were able to state that "[c]osts per case for hospice care patients appear generally to be lower than costs for similar patients receiving more traditional care."

Since the average duration of hospice care varies substantially among local programs, it is useful to consider the reported average costs of a day of care for a patient in a hospice program. As indicated in Table 8, these costs are in the range of $60–$90 per day. The average period of care tends to be 40–50 days.

The reported average daily costs of regular hospital care for terminally ill cancer patients are considerably higher. As indicated in Table 9, when adjusted for inflation, such costs tend to fall in the $300–$400 range. These figures are probably conservative since they do not fully reflect the costs of new methods of cancer treatment that have been introduced in recent years.

TABLE 8.—REPORTED COSTS OF A HOSPICE PROGRAM DAY (COMPREHENSIVE SERVICES)

| Location | Year | Average days of care | Average daily costs |
|---|---|---|---|
| Boonton, N.J | 1980 | 56 | $57.00 |
| Arizona study | 1980 | 49 | 61.22 |
| Jacksonville, FL | 1980 | 29 | 72.36 |
| Tucson, Ariz | 1980 | 44 | 73.00 |
| Rochester, N.Y | 1978 | 28 | 75.28 |
| Los Angeles, Calif | 1980 | 52 | 88.00 |
| California study | 1980 | 62 | 88.09 |

TABLE 9.—REPORTED COSTS OF HOSPITAL CANCER CARE OF TERMINAL PATIENTS IN THE ABSENCE OF HOSPICE CARE

| Location | Year | Average days of hospital care | Average daily costs | Adjusted daily costs [3] |
|---|---|---|---|---|
| Third national cancer survey | 1970 | [1] 31 | $90 | $205 |
| Rochester, N.Y | 1978 | [2] 17 | 225 | 277 |
| Hayward, Calif | 1977 | [2] 17 | 266 | 355 |
| Jacksonville, Fl | 1978 | [2] 22 | 278 | 342 |
| Philadelphia, Pa | 1079 | [2] 14 | 370 | 414 |
| California study | 1980 | [2] 20 | 400 | 400 |

[1] Patients who died within 6 months after cancer diagnosis.
[2] Estimates of hospitalization during period in which hospice care would have been provided.
[3] Adjusted for inflation in hospital costs between year of the study and 1980.

The average per patient cost of providing hospice care was reported by the recent NCI study to be $3,660. Therefore, if the average cost of caring for a terminally ill cancer patient is $400 per day, the saving of some 9 days per patient would pay for all hospice costs, not just added costs. As Table 9 indicates, existing studies have estimated savings ranging from 14 to 22 days per average patient.

These savings resulting from the substitution of hospice for inpatient care have been documented by several studies. For example, a hospice care program in Rochester (N.Y.) sponsored by the Genesee Region Home Care Association reported 1,576 days of hospice care in 1978 to 55 patients at a cost of $118,626. Had these patients not received such care and been cared for normally, their physicians estimate that 943 additional hospital days of care—an average of 17 days per patient—would have been required at a cost of $212,175. Thus, there was a reported total saving of more than $93,000, an average saving of about $1,700 per patient.

A study at the Kaiser-Permanente Medical Center in Hayward, California, in 1978, compared 62 inpatient hospice patients to 45 non-hospice hospital patients and found that hospice care reduced the costs of caring for cancer patients an average of $813 per patient for care during the last 60 days of life. The hospice care in that program was essentially inpatient care since the Center's home care program was still being established at the time. Increases in nursing and team care were reported to have been more than offset by reductions in ancillary services. The authors concluded that the incremental costs of hospice care under the then existing hospice care program did not add to the costs to Kaiser of caring for terminally ill patients.

In 1980, the staff of the California Department of Health Services compared hospice care in four local programs with "traditional care" for terminally ill persons and identified potential net savings of about $2,100 per patient where hospital costs were $400 per day. The saving was the equivalent of 5 hospital days over and above the reduction in hospital services that offset the added costs of hospice care. The estimates of potential savings per patient served ranged from $924 to $2,646 among the four hospice programs. The report notes that the analyzed data "strongly suggest that participation in the hospice project significantly reduces the patient need for hospital services, the most expensive service provided to patients dying of cancer."

TABLE 10.—POTENTIAL COST SAVINGS

[Millions of dollars]

| | Kaiser study ($800) [1] | | Rochester study ($1,700) [2] | | California study ($2,600) [3] | |
|---|---|---|---|---|---|---|
| | Assumption 1 [4] | Assumption 2 [5] | Assumption 1 [4] | Assumption 2 [5] | Assumption 1 [4] | Assumption 2 [5] |
| 1982 | 13.6 | 16.8 | 28.9 | 35.1 | 44.2 | 49.6 |
| 1983 | 18.4 | 23.9 | 39.1 | 49.9 | 59.8 | 70.4 |
| 1984 | 23.2 | 31.6 | 49.3 | 66.0 | 75.4 | 93.3 |
| 1985 | 28.0 | 40.0 | 59.5 | 83.7 | 91.0 | 118.2 |
| 1986 | 29.6 | 44.4 | 12.9 | 92.9 | 96.2 | 131.3 |
| Total | 112.8 | 156.7 | 239.7 | 327.6 | 366.6 | 462.8 |

[1] Based on study at Kaiser-Permanente Medical Center, Hayward, Calif., 1978.
[2] Based on study by Genesee Region Home Care Association, Rochester, N.Y., 1978.
[3] Based on study by California Department of Health Services, 1980.
[4] Assumes no difference in inflation rates between hospital costs and hospice costs.
[5] Assumes hospital costs increases 5 percent more per year than hospice costs.

Table 10 presents estimates of potential cost savings from the introduction of Medicare benefits for hospice care. Estimates are based on the findings of the three analyses discussed above—(1) the Kaiser-Permanente Medical Center program in Hayward, California; (2) the Genesee Region Home Care Association program in Rochester, New York; and (3) the California Department of Health Services study. These analyses reported potential savings of about $800, $1,700 and $2,500 per patient respectively. Information is also presented on the potential impact if the cost of hospital care rises 5 percent faster per year than hospice care due to the rapidly rising costs of technologically intensive treatment. It is estimated that the potential savings range from about $13 million to $50 million the first year and from about $30 million to $130 million the fifth year on an aggregate basis, taking account of both increased use of some services and reduced use of other services. These estimates are based on the "medium estimate" of program build-up set forth in Table 5. If the build-up of patients receiving authorized hospice care is more rapid, the potential savings woud be larger.

Indications from every reported review of hospice care costs and use (see Appendix C) indicate reductions in hospital use exceed the cost of services added, suggesting that it can safely be concluded that coverage by Medicare of comprehensive hospice care as proposed would not increase Medicare costs but seems very likely to reduce them.

*Reimbursement policy*

To ensure that Medicare payments for hospice care would not exceed expectations, the proposed bill includes a limit on payments for hospice care. The bill provides that the Secretary would establish limits—by region—on the average cost per patient of a hospice that woud be equal to 75 percent of the average cost of care for cancer patients during the six months preceding death.

The type of data required to set such limits was obtained in a study now being completed by HCFA. The bill would require that the limit for the initial year be set by the Secretary using the most recent data available. Thereafter, the medical care component of the consumer price index would be used to update the limits annually.

The 75-percent limit would ensure that costs would be modest, even if no cost-saving substitution of services were realized—a most improbable contingency. It also provides an incentive to hospice programs to develops more economical services, while maintaining a quality of care that is acceptable and attractive to Medicare beneficiaries, their familites and their physicians.

APPENDIX A

*Major sources of information on hospice care costs*

Amado, Anthony and others, Cost of Terminal Care; Home Hospice vs. Hospital, Nursing Outlook, August 1979, pp. 522-26.

Arizona College of Business and Public Administration, Empirical Study of Hospice Services in the United States, October 1980.

Bloom, Bernard and Priscilla Kissick, Home and Hospital Cost of Terminal Illness, Medical Care, May 1980, pp. 560-4.

Blue Cross and Blue Shield Associations, Hospice Survey Report, Selected Blue Cross and Blue Shield Association, 1980.
California Department of Health Services, Report to the 1980 California Legislature on the Hospice Project, 1980.
Cost of Disease and Illness in the United States in the Year 2000, Public Health Reports, September/October 1978, pp. 493–588.
Department of Health, Education, and Welfare, Report of Secretary's Task Force in Hospice, December 1978.
Department of Health and Human Services, Social Services Within the Framework of Hospice Care, 1980.
Fletcher, John and others, The Cost of Terminal Illness, 1981.
General Accountng Office, Hospice Care—A Growing Concept in the United States, March 1979.
Health Care Financing Administration, NHSQI Clearinghouse, Hospice Care, March 1981.
Health Care Financing Administration, A Report on the Costs of Terminal Illness, August 1981.
Health Resources Administration, Care for the Terminally, Ill: An Update on Hospice Issues and Operations, May 1981.
Hodgson, Thomas, Economic and Social Issues in the Treatment of Terminal Illness, 1981.
Joint Commission on the Accreditation of Hospitals, An Interim Report on the JCAH Hospice Project, July 1981.
Lubitz, James and others, Use and Costs of Medicare Services in the Last year of Life, August 1981.
Methodist Hospital, Jacksonville, Florida, Study of Terminally Ill Cancer Patients, July 1973 through June 1978.
Mount, BM, Hospice Care, Journal of the Royal Society of Medicine, July 1980.
National Cancer Institute, Report of the Third National Cancer Survey: Hospitalizations and Payments to Hospitals, March 1976.
National Cancer Institute, A Cost Analysis of Three Hospice Programs, July 1981.
National Clearinghouse for Improving the Management of Human Services, Project Share, Care of the Terminally Ill—The Hospice Concept, December 1980.
National Hospice Organization, Delivery and Payment of Hospice Servies: Investigative Study, September 1979.
Van Buren, Linda, Hospice Home Care: A Cost Analysis of a Sample of Patients Seen During 1980, Home Health Review, September 1981, pp. 10–13.
Veterans Administration, Wadsworth Hospice Evaluation Study, July 1981.
Walter, Norman, Hospice Pilot Project Report, Kaiser/Permanente Medical Center, Hayward, California 1979.
Western Center for Health Planning, Issues in Planning for Hospice Services: An Introduction, December 1980.

## Appendix B

*Selected data reports on proportion of patients served by hospices with diagnosis of cancer*

| Hospice or study: | Percent of patients with cancer: |
|---|---|
| "Analyzing the Hospice Markets" Hospital Progress 60:10, October 1979, 52–55. | |
| Methodist Hospice, Methodist Hospital, Jacksonville, Fla., June 1, 1981. | Over 90 |
| Second year evaluation—Washington home hospice program. | 100 |
| Hospice care survey repoort, selected Blue Cross and Blue Shield plans, 1980 Blue Cross/Blue Shield Assn., September 1, 1981. | "Most" in six reporting places |
| Hospice pilot project report, Kaiser/Permenente Medical Center, Hayward, Calif., 1979. | 95 |
| Virginia Department of Health, interim report to the Governor and General Assembly of Virginia, House Document No. 9, 1980. | 90 |

| Hospice or study: | Percent of patients with cancer: |
|---|---|
| "Hospice Care—a Growing Concept in the United States," General Accounting Office, HRD79-50, March 6, 1979. | "Primarily serve cancer patients . . . have served a few patients in the terminal stage of kidney failure and heart disease" |
| "Empirical Study of Hospice Services in the United States" University of Arizona, October 1981. | 94.5; low 74, high 100 among 24 hospices |
| "A Plan for a System of Hospice Care"—Cleveland HSA. | Assumed 90 |

APPENDIX C

REPORTS OF COST CONSEQUENCES OF HOSPICE COVERAGE

| Source [1] | Location | Date | Conclusion |
|---|---|---|---|
| Amado Anthony, et al | Genesee region, Rochester, NY. | 1978 | $1,700 saving per patient served. |
| Bloom and Kissick | Pennsylvania | 1979 | $5,600 difference in average cost between those dying at home and in hospital. |
| Mount, B.M. | Royal Victoria Hospital, Canada. | 1980 | Reduction of hospital use by average of 20 days per patient. |
| California Department of Health Services. | California | 1980 | $2,133 per patient served; "although the potential cost savings to the Medical program from hospice care may be substantial, the data are only suggestive." |
| Van Buren, Linda | Not stated | 1980 | $2,559 saving per patient. |
| Walter, Norman | Kaiser Hayward Hospital, Calif.. | 1979 | $800 saving per patient served. |
| Blue Cross and Blue Shield Associations. | 3 plans | 1980 | "Costs per case for hospice care patients appears generally to be lower than costs for similar patients receiving more traditional care." |

[1] Reference is to list of major sources of information on hospice care costs (appendix A).

Mr. ZIER. That analysis, as you have heard this morning, concludes that passage of 5180 and the substitution of the hospice benefit for the array of already covered medicare benefits, will incur no cost increase and will quite likely result in a net savings to the Federal Government.

Some measure of support for this resolution, as once again has been mentioned this morning, can be seen in the bipartisan flavor of commitment to this resolution, with more than 200 Congressmen and Senators showing their support. That number grows every day.

Warner-Lambert Co. is joined by many in this Nation's business community in urging that you do not delay or dilute House Resolution 5180. We respectfully recommend that you favorably pass it onto the full House of Representatives.

Thank you, Mr. Chairman.

[The prepared statement follows:]

STATEMENT OF RONALD E. ZIER, VICE PRESIDENT, PUBLIC AFFAIRS, WARNER-LAMBERT CO.

My name is Ronald E. Zier, Vice President of Public Affairs, Warner-Lambert Company, headquartered in Morris Plains, New Jersey. With me is Ewart Thomas, our Director of Community and Public Affairs, who has been closely associated with the hospice movement.

Warner-Lambert is a major health care company with 1981 sales approximating $3.5 billion. We have requested to testify in support of H.R. 5180 to amend Title XVIII of the Social Security Act to provide for coverage of hospice care under the Medicare program.

Warner-Lambert has been involved in the hospice movement for about five years. This participation has ranged from the donation of executive time to the underwriting of booklets, newsletters and a documentary film on the subject of hospice.

As a socially responsible corporate citizen in the health care industry, we are very much concerned about problems facing the health care delivery system. The demographic patterns in this country clearly demonstrate that our population is getting older and that our senior group represent an increasingly large segment of our population. That's a matter of record. As are the government's statistics showing that one out of three Americans who reach the age of 74 will be affected by cancer.

Warner-Lambert supports H.R. 5180. We believe it addresses the humanitarian needs of an aging society, as well as responding to the issue of health cost containment. As I said, we have supported the growth and development of the hospice concept in the United States since 1977. Our latest support of hospice was the commissioning of a cost and fiscal impact analysis statement relating to H.R. 5180. Developed for us by Health Policy Alternatives, Inc., the study is attached to our official written testimony. It should be noted that the study concludes that hospice could represent a potential cost savings of at least $13 million the first year. This figure is expected to rise to at least $30 million per year following the fifth year of enactment.

It should also be noted that other major corporations and insurance companies have begun to join the hospice movement by offering hospice medical benefits to employees, dependents and clients. Warner-Lambert has added hospice benefits to its medical benefits program for employees and their dependents as of January 1, 1982.

We are pleased to have the opportunity to offer our testimony today in support of H.R. 5180 and respectfully recommend your support.

Mr. RANGEL. Congratulations to Warner-Lambert Co. for its progressive attitude in terms of employee benefits.

Mr. Duncan.

Mr. DUNCAN. Thank you, Mr. Chairman.

Mr. Hollander, you say that hospice care can be cost effective when implemented carefully. Would you share with the subcommittee what you perceive really to be cost-effective characteristics of the hospice program?

Mr. HOLLANDER. Well, in a simple sense, you could say that if the quality of care remains the same or higher, and the costs of care are no more than we would spend normally using some alternative means of providing care, then it is cost effective. I think in my testimony I said many of our experiences and demonstration projects show that.

But the richness of the demonstrations show large variations between the costs of care. In some places we have seen some instances where the costs of care seem to be parallel to the type of care we think we would provide normally in the absence of hospice. In some cases, particularly those programs that emphasize home care and an interactive relationship with the community, the costs of care seem to be less.

And clearly, the people that participate in hospice are very satisfied under both circumstances.

Mr. DUNCAN. Have you found cases where the cost is much greater than the inpatient care?

Mr. HOLLANDER. Yes. Almost by definition, when a program emphasizes inpatient care as an alternative to home care, the costs are likely to be higher. You cannot forget, though, any program, irrespective of its emphasis, is going to have to use a certain amount of inpatient care, whether in a free-standing hospice or as part of another provider.

But the ones that emphasize home care and community involvement seem to have—and I emphasize "seem," because there are

almost as many different kinds of hospices as there are demonstration projects that we have under way—they seem to reduce the amount of inpatient care.

Mr. DUNCAN. Mr. Neiswanger, did I understand you correctly, I hope I did not—did I understand you to advocate the payment of bereavement counseling?

Mr. NEISWANGER. We are going to include bereavement counseling in the program, with a limited number of visits we are going to offer to small policyholders. We have seen that a part of the hospice benefit, that some of the large corporations have wanted to include. It is something we have really very little experience with, since we have not covered it under traditional insurance programs.

I think if the visits are limited, if the hospice agency is a good agency, and we are trying again to use the hospice standards, that that could probably be controlled without a boost.

Mr. DUNCAN. Do you not think that is something that our pastoral community should handle? Have we just forgotten altogether the good Samaritan-type of human service from one person to the other? It kind of struck me really hard. I think, Mr. Goldbeck, you mentioned that also, that you favor that.

I think you were the first to mention it. I was just surprised—particularly in your field—that you want to get paid for bereavement service.

Mr. GOLDBECK. I am not a provider and I do not want to get paid for bereavement services. We want medicare to recognize the medical validity of this care, and to reimburse for it. Unfortunately our society is not one in which everybody is involved in pastoral programs. That is a value issue that causes great concern. But it is also a reality. And there is also the reality that through the medical care systems we pay now for the impact of emotional distress resulting from loss of family members. This is not a matter of a new issue, but rather of adding a new solution to a very old problem.

We pay for that problem now through incredible amounts of absenteeism, medical care for the psychological and physiological impacts of emotional problems and stress. The cases brought before you earlier today demonstrate that assistance for the involvement of that family was a critical element of enabling them to provide a quality home care setting, to return to work, and to conduct their normal lives in a reasonable fashion.

And so we feel bereavement care on a managed basis is recognition of a problem that in fact exists and is amenable to a counseling kind of assistance.

Mr. DUNCAN. My family has been through this situation three times in the last 2 years. I think things like that are some of the reasons that some Members of Congress are apprehensive about new programs, that we add all the fringes and the frills to it.

I have no further questions. I do want to thank the panel.

Chairman JACOBS. The subcommittee expresses its gratitude to the panel. I regret not having heard the panel myself. I will read the testimony.

Thank you.

The next panel includes Dr. Robert Enck, Carole Shields, Mr. Robert Milch, and Jo Ann Bouda.

Ms. Shields, our former colleague, Mr. Buchanan, asked that we express a special welcome to you.

Ms. SHIELDS. Thank you.

Chairman JACOBS. You may proceed in your own manner. You each know that you can submit a formal statement for the record and summarize if you choose to do so.

I expect we are under the 5-minute rule now for each item of testimony.

Please identify your organizations.

## STATEMENT OF ROBERT ENCK, M.D., ASSOCIATION OF COMMUNITY CANCER CENTERS

Dr. ENCK. I am Robert Enck, I am a physician from Binghamton, N.Y. My specialty is oncology and I direct both the oncology program and hospice program at Lourdes Hospital. I am here today as representative of the Association of Community Cancer Centers (ACCC).

The membership of the Association of Community Cancer Centers, like many others you have heard today, is concerned about the lack of adequate reimbursement for hospice or terminal care services.

Since 85 percent of cancer patients are treated in the community, our membership now accounts for treating one out of every four cancer patients in the United States.

Three-fourths of our delegate members have a functioning hospice as an integral part of their cancer care program.

Rather than viewing hospice care as an alternative health care system, we believe hospice is an important component of the ongoing continuum of care for the cancer patient and family.

The goals of hospice care are to maximize the quality of life, regardless of the length, for the dying patient and to provide support for the patient's family.

These goals are also shared by the other elements of the cancer care program, including the treatment-oriented phase.

Any proposed hospice legislation should reflect the integration of hospice care into the health care delivery system rather than in isolation.

The importance of this integration is underscored by the National Cancer Institute's recently funded community hospital oncology program (CHOP).

By contractual agreement, each of the 23 CHOP's must plan and implement a terminal care program as part of the required scope of work.

There are several issues which we believe need some resolution when you begin to consider funding hospice. These are not insurmountable obstacles, but we believe you will need to resolve them before you begin this new program.

First, where do you draw the line between conventional care and hospice care? Hospice care is not just TLC or tender loving care. It is also the management of a person's physical pain and comfort.

Throughout the initial legislation that you are reviewing and the interpretive congressional handouts, there are a diversity of terms

such as "palliative," "curative," and "aggressive acute therapies," which are poorly defined and less well understood.

For example, a hospice patient with a painful bone metastases not responding to adequate treatment with analgesics can be "palliated" with localized radiation therapy.

Likewise, a patient with a pain-rendering bowel obstruction due to recurrent colon cancer and not responding to conservative management can be "palliated" by a surgical procedure to bypass the obstruction and relieve the discomfort.

These examples are relatively straightforward.

Is the hospice patient who full well understands that he/she is dying, but is insistent that he/she continue to be treated with chemotherapy despite the fact that a chance of responding is very slight, undergoing "curative" or "aggressive acute therapy"?

Should we deny this patient the right to receive therapy? Or to receive hospice? Should the hospice patient who breaks a hip in a fall undergo "aggressive acute therapy" in an acute care facility with shifting of medicare benefits?

In this case, where is the continuity of hospice care?

To those of us caring for cancer patients on a daily basis, the last two examples are more artificial than real.

As health care professionals involved in hospice, we are concerned with alleviation of pain and symptoms, both in the physical and spiritual realms.

And we realize that these are major issues which remain to be resolved.

A second concern is the role of various types of physicians in management of hospice patients. This relates to the continuity of care which I discussed before.

Hospice care is not a physician-dominated service. In fact, the services provided by other members of the interdisciplinary team (registered nurse, social worker, volunteer, pastoral, or other counselor) are often more important.

Thus, the position of hospice medical director is not necessarily full time and tends to emphasize education and liaison with the medical community.

It, also, involves being available to the interdisciplinary team, working with pain and symptom management and serving as a community liaison.

In the proposed legislation, the hospice medical director and attending physician certify the individual is terminally ill and subsequent recertification at 90-day intervals is done by the hospice medical director alone.

This, in effect, would subjugate the role of the attending physician, who, as defined in the proposed legislation, is "the physician (as defined in subsection (r)(1)) whom the individual identifies as having the most significant role in the determination and delivery of medical care to the individual at the time the individual is to be provided hospice care."

Who better understands the continuum of care and needs of the patient and family than the attending physician? This physician, who is legally responsible for the patient, has, in many cases, helped the patient and family through the trauma of the diagnosis of cancer and through the rigors of treatment.

We must strive to include, not exclude, the attending physician's role in hospice care. Therefore, after the patient and family's acceptance into hospice care, the attending physician should certify the patient's terminal status as well as the recertification at 90-day intervals.

Likewise, the attending physician should be involved in planning for bereavement counseling for the family.

In these ways, we will keep this type of physician involved with our patients and not make hospice a separate health care system.

A third concern is the cost of hospice care. As I noted at the outset, the members of ACCC strongly believe that hospice should be reimbursed—but not at all costs.

There are a couple of issues that I have heard discussed which really need research. Predictability is a major problem. Some physicians say they can tell you 6 months out when someone is going to die.

Others will tell you they are uncertain until 20 minutes before death.

Also, the length of time of the benefit is a baffling problem. Consequently, many patients come to hospice just a few weeks before death. Others come earlier.

And many go to nursing homes, which they can afford, rather than hospice, which is not reimbursed.

If you provide the benefit too late, you may have patients going to nursing homes instead of hospice.

Once in a nursing home, they are unlikely to return to hospice. If you provide it too early, I can see how hospices could have a great many patients who outlive the benefit period or who go back to "conventional" care.

Patient flow will be very tricky.

We agree with the American Medical Association that more research and study on cost savings is necessary and, hopefully, the ongoing HCFA study, as well as others, can supply the data.

In summary, ACCC feels hospice reimbursement is very important, but further study of the ways this can be cost effective and good for patients and their families need to be done before this is enacted.

Hospice is an important part of the continuum of care. The emotion and advocacy of the issue must be set aside so clear thinking can prevail to enact legislation that will benefit the thousands of cancer patients in the United States.

Thank you.

[The prepared statement follows:]

STATEMENT OF ROBERT ENCK, M.D., ACCC REPRESENTATIVE

My name is Robert Enck. I am an M.D. from Binghamton, New York. My specialty is oncology and I direct both the oncology program and hospice program at Lourdes Hospital. I am here today as a representative of the Association of Community Cancer Centers (ACCC).

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The goals of hospice care are to maximize the quality of life, regardless of the length, for the dying patient and to provide support for the patient's family. These goals are also shared by the other elements of the cancer care program including the treatment-oriented phase.

Any proposed hospice legislation should reflect the integration of hospice care into the health care delivery system rather than in isolation. The importance of this integration is underscored by the National Cancer Institute's recently funded Community Hospital Oncology Program (CHOP). By contractual agreement, each of the 23 CHOPs must plan and implement a terminal care program as part of the required scope of work.

There are several issues which we believe need some resolution when you begin to consider funding hospice. These are not insurmountable obstacles, but we believe you will need to resolve them before you begin this new program.

First, where do you "draw the line" between conventional care and hospice care? Hospice care is not just T-C-L, (tender loving care). It is also the management of a person's physical pain and comfort.

Throughout the initial legislation that you are reviewing and the interpretive congressional handouts, there are a diversity of terms such as "palliative", "curative" and "aggressive acute therapies", which are poorly defined and less well understood.

By definition, an individual with a medical prognosis of six months or less to live is deemed terminally ill and eligible for hospice care as distinguished from "conventional" therapy. However, a hospice patient with a painful bone metastases not responding to adequate treatment with analgesics can be "palliated" with localized radiation therapy. Likewise, a patient with a pain rendering bowel obstruction due to recurrent colon cancer and not responding to conservative management can be "palliated" by a surgical procedure to bypass the obstruction and relieve the discomfort. These examples are relatively straight forward and take place frequently.

Is the hospice patient who full well understands that he/she is dying but is insistent that he/she continue to be treated with chemotherapy despite the fact that a chance of responding is very slight undergoing "curative" or "aggressive acute therapy"? Should we deny this patient the right to receive therapy? Or to receive hospice? Should the hospice patient who breaks a hip in a fall undergo "aggressive acute therapy" in an acute care facility with shifting of Medicare benefits? In this case, where is the continuity of hospice care?

To those of us caring for cancer patients on a daily basis, the last two examples are more artificial than real. As health care professionals involved in hospice we are concerned with alleviation of pain and symptoms both in the physical and spritual realms. And we realize that these are major issues which remain to be solved.

A second concern is the role of various types of physicians in management of hospice patients. This relates to the continuity of care which I discussed before.

Hospice care is not a physician dominated service. In fact, the services provided by other members of the interdisciplinary team (registered nurse, social worker, volunteer, pastoral or other counselor) are often more imortant. Thus, the position of hospice medical director is not necessarily full time and tends to emphasize education and liaison with the medical community. It, also, involves being available to the interdisciplinary team, working with pain and symptom management and serving as a community liaison. In the proposed legislation, the hospice medical director and attending physician certify the individual is terminally ill and subsequent recertification at 90 day intervals is done by the hospice medical director alone. This, in effect, would subjugate the role of the attending physician who, as defined in the proposed legislation, is "the physician (as defined in subsection (r)(1)) whom the individual identifies as having the most significant role in the determination and delivery of medical care to the individual at the time the individual is to be provided hospice care".

Who better understands the continuum of care and needs of the patient and family than the attending physician? This physician, who is legally responsible for the patient, has, in many cases, helped the patient and family through the trauma of the diagnosis of cancer and through the rigors of treatment.

We must strive to include, not exclude the attending physician's role in hospice care. Therefore, after the patient and family's acceptance into hospice care, the attending physician should certify the patient's terminal status as well as the recertification at 90 day intervals. Likewise, the attending physician should be involved in planning for bereavement counseling for the family. In these ways we will keep this

type of physician involved with our patients and not make hospice a separate health care system.

A third concern is the cost of hospice care. As I noted at the outset the members of ACCC strongly believe that hospice should be reimbursed . . . but not at all costs!

Predictability is a major problem. Some physicians say they can tell you six months out when someone is going to die. Others will tell you they are uncertain until twenty minutes before death. Some of us see a large number of cancer patients, but non-specialists only see a few. This accounts for more patients than you might suspect. Roughly half of all cancer patients are admitted to hospitals by physicians who see ten or less cancer patients a year. So they may see too few to accurately predict when the patient is terminal or when they will die.

Also, the length of time of the benefit is a baffling problem. Currently, many patients come to hospice just a few weeks before death. Others come earlier. And many go to nursing homes, which they can afford rather than hospice, which is not reimbursed. If you provde the benefit too late, you may have patients going to nursing homes instead of hospice. Once in a nursing home they are unlikely to return to hospice. If you provide it too early, I can see how hospices could have a great many patients who outlive the benefit period or who go back to "conventional" care. Patient flow will be very tricky.

Preliminary information suggests that hospice care is less expensive than conventional care because of a reduction in the number of hospital days and a reduction in the use of expensive services during hospitalization. More research and study on cost savings is necessary and, hoepfully, the ongoing HCFA study as well as others can supply the data.

In summary, ACCC hospice reimbursement is very important, but further study of the ways this can be cost effective and good for patients and their families, need to be done before this is enacted. Hospice is an important prt of the continuum of care. The emotion and advocacy of the issue must be set aside so clear thinking can prevail to enact legislation that will benefit the thousands of cancer patients in the United States.

Mr. JACOBS. Six minutes, twenty-seven seconds. There are lights to indicate the 5-minute limit.

The next panelist is Ms. Shields.

## STATEMENT OF CAROL SHIELDS, CONSULTANT, ARTHUR VINING DAVIS FOUNDATIONS

Ms. SHIELDS. Thank you, Mr. Chairman.

With your willingness to accept my written statement, I will make a few comments.

Chairman JACOBS. Fine.

Ms. SHIELDS. I am a resident of Tennessee and consultant to the Arthur Davis Foundation, in Jacksonville, Fla.

The foundation has a grant of $3 million a year and a good portion has gone to medicine in the past.

About 5 years ago, when hospice began to surface, we decided to take a close look to see what it was all about and decide what we wanted to do about it, if anything.

That means we have had to evaluate the same service definitions and fiscal issues and even some of the same people that you are trying to understand.

We decided after looking at it that--that was before definitions had been done by the National Hospice Organization. After studying it and listening to a lot of people talk, we decided there were things that had to exist for us to consider the hospice, like bereavement care, 24-hour availability of care, medical direction, home care emphasis, that kind of thing.

One of the reasons I am here is that all of that is present in this bill. We support the bill.

Also, I wanted to comment on the fact that hospice is, to this point, pretty much a child of the private sector. It is an experiment that has been funded largely by private means.

I think that probably cannot go on forever because we have done it in the face of disincentives.

The medicare system has worked against us from the beginning. That is OK, but it is time that that needs to change.

The first point is that the definition has to be there. I would urge you not to let anybody talk you out of those items that make hospice what it is.

The other thing is that you should resist any attempt to change the provision that hospice is a separate category of care.

If you pass the bill, the incentive for private and voluntary involvement will be preserved. However, private money won't go toward brokerage cost—expensive service, maybe inappropriate services, the things that gave rise to the development of the hospice movement in the first place. That part is important.

If the bill is not passed now, we are going to lose some hospices. I think they are going to be the ones that serve the poor, the hospices in the rural areas and we just need the bill.

Thank you.

[The prepared statement follows:]

STATEMENT OF CAROL SHIELDS ON BEHALF OF ARTHUR VINING DAVIS FOUNDATIONS

I am here to support the passage of H.R. 5180 as it is written. My concern for hospice began five years ago when I was program officer for a philanthropic foundation of national scope. After two years of investigation into the issues surrounding the development of hospice in this country, the foundation established a formal program focus in hospice. That means that I have been in your place. I have had to evaluate the same service definitions, the same fiscal issues, and the same people that you are attempting to understand here. I have evaluated, in one form or another, between one-quarter and one-third of the operating hospices in the country. Our grants supported the first national study of reimbursement practices, organizational meetings of regional groups of hospices, training events for hospice caregivers, and gave direct support to individual hospices in a dozen states.

I am here as a volunteer—on my own time—because this bill meets the standards that we (and many others in the foundation world) determined were necessary to warrant our support. I'm here because this bill defines a comprehensive program of care for patients and families that has been tried, is working, and deserves to be preserved. That can be done only by the passage of this bill.

The term "hospice" is currently used in a variety of settings. Some of these programs do not choose to deliver the coprehensive care that is described in this ill as hospice. In our work at the foundation, we had to settle on a working definition. We refused to consider an applicant as representing hospice unless certain elements were presnet, for example: 24-hour, 365-day a year availability of care; care regardless of ability to pay; volunteer involvement throughout the program; presence of a medical director; and planned and international bereavement followup care.

To remove even one of those elements is to profoundly impact the expreience of the patient/family. To alter the nature of hospice during this process (as is quite possible) is also to toy with the basic reasons for the influx of priviate money to an experiment which was discouraged at every step by the existing reimbursement system.

The argument has been made that it isn't necessary that this bill include coverage of all services—that items eliminated from the reimbursement package can be picked up by private donations. While in theory that may sound reasonsable, it ignores a fact of life of the health care system—the availability of dollars will in fact define and service. The result of the final form of this bill will be to provide either incentive or disincentive for legitimate hospice development.

The aspect of this total package of care that probably best illustrates both the strength of hospice (the total plan of care) and the potential effects of only partial reimbursement is bereavement care. It is impossible to conceive of believable, re-

sponsible relationship with a family with a dying member if there is impending abandonment on the day following death. The needs simply don't stop. Preservation of the underlying assumptions which founded hospice demands attention to the grieving family a bereavement care is also quite pertinent to the question of whose care someone will be paying for next. Wellness and grief-related illness are issues which should concern any health care reimburser. If bereavement followup is eliminated here, however, it is naive to assume that it will automatically materizalize on its own. The real world scenario includes the protest of those who would like to provide such care, but who determine that it just can't be afforded. In their defense, remember that they will be supporting through private; means all of those patients (an expected 30 percent) who are not of medicare age. What is reimbursed for medicare patients is what will exist for medicare patients.

In the mid-70's, hospice came to our attention sporting a number of adornments which appealed to the thinking of private foundations and private citizens.

It told us the story of better care—an alternative to imprisonment by inappropriate curative measures;

It acknowledged persons rather than deseases;

It spoke of like rather than death;

It brought together a number of disciplines, making the whole more than the sum of its parts;

It worked, and

Because it worked, it unleasehed and activated the people—people and their churches, their businesses, their money and their commitment.

For quite awhile, most of the developing programs we saw were strictly volunteer arrangements; doctors, nurses, ministers, social workers who donated their time to care for patients and their families. A church or business would donate some office space, others would provide the furniture. Someone else would pay the phone bill each month. I've seen excellent care provided by such volunteer home care teams. But what happens when the daily census in a city of half a million quite predictably climbs past the extremely small daily census that they can handle? I know of a program right now that is operating on a budget of $130,000. The United Way contributes $37,000 of that. There is a constant struggle to keep enough grants and contracts for eductional services coming in to survive. The community is active in its support; however, there isn't enough to go around, particularly with the demand on the private and voluntary sectors increasing daily.

I favor this bill because it presents a reasonable partnership between private philanthropy and government. The private sector has done an impresssive job in funding the experiment and proving the worth and validity of the concept. It is not reasonable, however, to expect that support to continue indefinitely in the face of a medicare system which continues to punish more appropriate and cost effective hospice alternatives. With passage of this bill, however, the incentive for private and voluntary involvement will be preserved. Private money will go toward providing for the 30 percent of hospice patients who are not medicare eligible. We will not be asked to fund a brokerage service for existing services of high cost and questionable appropriateness. We will see protection from fraud and abuse because those who are paid will be those who are responsible for and who are delivering the care. In order for hospice care in the U.S. to be possible, you must resist attempts to eliminate the section of the bill which establishes hospice as a separate category of care. Private money will not go to pay for care which is merely a combination, a rearrangement or a marketing device for the curative and chronic services which gave rise to the need for hospice in the first place.

What happens if you do not accept this bill? Which hospice programs, in which cities, in which socio-economic brackets will still be here in three years? Those that are true alternatives, that do cost less, those in rural areas, those that serve the poor—they will not be the survivors.

To decide not to pass this bill is to decide for the loss of hospice. We in the private and voluntary sectors have done our homework, and present you with a hard fought program of integrity. Now you must do your part. We need this bill.

Mr. JACOBS. Thank you. That was only 2 minutes and 43 seconds, by the way.

## STATEMENT OF ROBERT A. MILCH, M.D., MEDICAL DIRECTOR, PALLIATIVE CARE SERVICE, BUFFALO GENERAL HOSPITAL

Dr. MILCH. Mr. Chairman, this bill is a laudable first attempt at giving meaning to the recognition that we in the medical and allied

health care professions have had for some time, that the needs of the terminally ill are not well met by our present health care delivery system.

As one who for 4 years has been involved with a multiphasic hospice program which has received no reimbursement, it is with a great sense of disappointment that I cannot support this proposed legislation in its present form.

We in the fledgling, but burgeoning field of hospice care can, in large part, attribute our success to three critical factors: first, our perception of the need for hospice care is identical to the perceptions of the lay community; second, we have, by and large, as did our predecessors in Britain and Canada, restricted our patient population to those dying of malignant disease, thereby dealing with a patient population which has a reasonably predictable disease trajectory and with medical needs which could be well met by a relatively small cadre of professional care givers and volunteers, and third, by dealing with a finite patient population whose care history acted as its own historical control, we have been able to embark on a mechanism for insuring quality performance by the evolution of guidelines established by the National Hospice Organization, and soon to be formalized by the Joint Commission on Accreditation of Hospitals.

The present legislation is a departure from this past course. I see in it no commitment to an experienced accreditation process or agency which would help assure the quality of the care being given.

While I am certain that the regulations to be promulgated by the Secretary will take some steps toward such a procedure, it would seem only prudent that he have recourse and reliance on the experience of those who have given this care in the past, such as the National Hospice Organization, or their designee, such as the Joint Commission on Accreditation of Hospitals, and that such a commitment be mandated as part of the law.

But most worrisome of all, I see no intent in the present legislation to limit the scope of the patient population to be served.

In its present form, the legislation would reimburse for services to patients with end-stage lung disease, end-stage heart disease, end-stage liver disease and end-stage neurologic disease, areas in which hospice programs have had minimal experience in the past.

By so doing, it may well create a situation in which the quality of care will be difficult to oversee or assess and the costs will be impossible to control.

I see no evidence that retrospective analysis of health care costs, to which reimbursement is to be linked, have been undertaken for any disease category save cancer and I fear the costs for other categories may well be in excess of what has been projected.

How ironic that the promise of the concept of care and the programs by which it is given life, originally intended for patients with malignant disease—unquestionably the most maligned and ill-treated segment of the terminally ill population—should be threatened by a well-meaning proposal that would create such a glut of demand that the needs of those dying of malignant disease might no longer be met by those programs.

Far better, I would think, to restrict this legislation to patients with malignant disease for a period that would allow examination and assessment of its impact.

Far better to include in this legislation a formal commitment to the laudable intents of the hospice philosophy, so that the highest possible quality of care might then assure the highest possible quality of life.

Thank you.

Chairman JACOBS. Thank you very much.

Three minutes, thirty seconds. OK, next.

## STATEMENT OF JO ANN BOUDA, ACTING DIRECTOR, HOSPICE SERVICES, HOSPICE OF RENO COUNTY, INC.

Ms. BOUDA. Members of the subcommittee, I thank you for this opportunity to testify on behalf of hospice care in the United States.

I am Jo Ann Bouda, acting director of Hospice Services, on a volunteer basis for the Hospice of Reno County, located in the State of Kansas.

My husband, Dr. David Bouda, is a practicing oncologist in Hutchinson, Kans., and medical director of this new hospice.

I will vary from my testimony at this point. I would like to make a few brief comments.

I do represent rural America in a very clear way.

We have a population of 63,000-and-some-odd people in the area we cover. We can study the cost effects of hospice on only a short basis, since we are a very new one.

Let me say our community has received this concept with great enthusiasm. The volunteers we have used now and trained are a phenomenal amount.

We have planned sessions to train additional volunteers in this calendar year.

I do want to say that I feel that the training and education of the general public in hospice principle will help return the feeling of responsibility to the families and communities to care for their sick and their dying, therefore, I think, helping to curb increasing medical costs and added responsibilities to the Government and medical insurance systems in our country.

If we can reduce the numbers of patients using institutions for their dying process, and increase the hands-on care of their families and community members, using the support systems which hospice principles can provide, there is no doubt that we will save Federal dollars and insurance dollars in our country.

Thank you.

[The prepared statement follows:]

STATEMENT OF JO ANN BOUDA, ACTING DIRECTOR OF HOSPICE SERVICES, HOSPICE OF RENO COUNTY, INC., HUTCHINSON, KANS.

Members of Congress, I thank you for this opportunity to testify on behalf of hospice care in the United States.

I am Jo Ann Bouda, Acting Director of Hospice Services, on a volunteer basis for the Hospice of Reno County located in the State of Kansas. My husband, Dr. David Bouda, is a practicing Oncologist in Hutchinson, Kansas and Medical Director of this new Hospice.

Reno County Kansas is a rural area with agriculture and light industry as an economic base. The county has a population of 63,720 and the lone Hcspital has a service area of 108,467.[1]

Hutchinson has a population of 39,000 and is a commercial center for 150-200,000 people.

The next largest hospital west, north or northwest is in Denver, Colorado. The Kearnes: Health Services Consultants have analyzed the market base, and active implementation of their recommended plan is underway to make Hutchinson Hospital Corporation a secondary referral center. The population 65 years of age and over is 8,576 in Reno County and 16,222 in the service area. This constitutes 15% of the population, 4% above the national average.[1]

Hospice serves older people who are both medicare patients and more susceptible to malignancy. In the years 1978 and 1979 Hutchinson Hospital Corporation had an average admissions per year for cancer of 460. This was prior to an oncologist arriving and the implementation of the Kearnes: Health Service Consultants Report (April 1981).[1] These numbers would be expected to increase as the program develops.

Based on statistics from the Health Planning Association of Western Kansas, one used in the Kearnes: Health Services Consultants Report (April 1981), the recorded deaths from cancer was 152 in Reno County. Based on formulae developed and applied in Ohio and Indiana[2,3] the number of those deaths that would have qualified for Hospice was as follows:

Total number cancer deaths per year (152) times estimated candidates for Hospice care (25%) equals number of cancer deaths utilizing Hospice (38 patients). Ten percent of the total is added for noncancer patients utilizing Hospice equals 4.

Therefore 42 patients would benefit from Hospice prior to the development of an active oncology program as is currently being implemented by Hutchinson Hospital Corporation and Dr. Bouda.

Based on statistics provided March 16, 1982 by Jim Berg, Vice President of Operations for Hutchinson Hospital Corporation, Medicare patients comprised 47.2% of hospital days and 33.7% of admissions. Reviewing a three month period ending January 31, 1982 an average non-surgical patient day cost $225.85 excluding physician fees.

An average Hospice patient is attended for an average of 60 days.[2] These days are for care of emotional, physical and spiritual needs. All active and potentially beneficial therapeutic intervention has been terminated prior to entry.

If our estimated 42 patients were attended for the average of 60 days the total days for Hospice care would have been 2,520 days. At the non-surgical per day cost of $225.85 this amount in the hospital would total $569,142.00. Current expected budget to operate Hospice of Reno County, Inc. would be $40,000 for 1982. If medicare would pay our operating expenses it would save $529,142.

Many patients for whom active therapeutic intervention remains may also benefit from Hospice care. Any time our volunteers or nurses can help maintain a patient out of the hospital and continue receiving outpatient treatment the medicare budget would save $225.85 per day in Reno County, Kansas.

We at Hospice of Reno County, Inc., believe strongly in utilizing patient, family and professional education and volunteer help. This combination can help all patients, not just those dying. We are working with the Hutchinson Hospital Corporation and the Reno County Health Department to implement a cooperative effort to accomplish our goals. Our road will be rocky and sometimes unmarked since we are the first over that road. With patience and help we can accomplish our goal. We strongly believe in the concept of Hospice in its broadest sense and that such application will reduce medicare costs and other Health Insurance costs significantly. If you divide the number of dollas for our Hospice budget by the number of Hospice days the cost per day would be $15.87. This is far less than $225.85 per hospital day.

Thank you for this opportunity to provide our views on the importance of funding hospice care.

Chairman JACOBS. Thank you. Very good.

Mr. Duncan.

Mr. DUNCAN. Thank you, Mr. Chairman.

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[1] Kearnes: Health Services Consultants Report, April 1981.

[2] Hospice Services in West-Central Ohio, West-Central Ohio Health Systems Agency, 616 South Collett Street, Lima, Ohio 45805 (April 1981), page 5.

[3] Northern Indiana Health Systems Agency, Inc., "Criteria and Standards for Hospice Services," April 23, 1980.

I wish to thank the panel. I have just one question for Dr. Enck.

In your testimony, you stated that special procedures to bypass obstruction and relieve discomfort for your hospice patients are performed frequently.

Can you tell us what percentage of your patients receive this type of treatment?

Dr. ENCK. I just use that as an example of palliation. As a matter of fact, it turns out to be rather infrequent. It is to relieve pain that a patient has of recurrent disease, the bowels don't work, they have pain, it is not removed by decompressive, which is a medical term for putting a tube in and letting the gas out, you then resort to a limited surgical procedure.

I use it as a "palliative" treatment.

Mr. DUNCAN. What do you mean by "infrequent," once a day, once a week, or once a month?

Dr. ENCK. Once every 6 months.

Mr. DUNCAN. Thank you, sir.

Thank you, Mr. Chairman.

Chairman JACOBS. Earlier today, the administration spokespeople said that the average hospitalization inpatient treatment for cancer, terminal illness, I take it, was 21 days.

This bill speaks of 180 days' hospice care. In light of that testimony by the administration, do you think that the savings implied by the testimony and by the legislation itself are quite so significant?

Anybody care to comment on that?

Dr. MILCH. If I may respond. I can respond only for my program, sir. An analysis was done by Blue Cross of western New York for us and Blue Cross estimates that the savings to them per patient per 6 months will be $3,587.

Chairman JACOBS. I think probably the answer is that the disparity in days does not necessarily reflect the disparity in cost, even though a minor number.

Dr. MILCH. I think that is a fair statement but they examined patients who had cancer.

Chairman JACOBS. Yes.

The committee is grateful to the panel for your contributions.

Thank you.

The next panel, I believe that we can hear now, is Mr. Peter Meek, Elizabeth Davis, and Patricia Page.

You know our procedure here. We ask you not to exceed 5 minutes in your presentation.

**STATEMENT OF PETER MEEK, MEMBER, BOARD OF DIRECTORS, NATIONAL HOMECARING COUNCIL, ACCOMPANIED BY ELIZABETH DAVIS, SECRETARY OF THE NATIONAL ASSOCIATION FOR HOME CARE; AND PATRICIA PAGE, VICE CHAIRMAN OF THE HOME HEALTH SERVICES AND STAFFING ASSOCIATION**

Mr. MEEK. Mr. Chairman, I am Peter Meek of Ridgewood, N.J., vice president of the National Home Caring Council.

To my right is Elizabeth Davis, of Burlington, Vt., the secretary of the National Association for Home Care; and then on her right is Patricia Page of Rockville Centre, N.Y., who is vice chairman of the Home Health Services and Staffing Association.

Both of them are providers of home health services in their home communities.

Our three organizations join in the statement that I have submitted to you in advance of this testimony. I am totally conscious of the hour and we will be as brief as possible.

Chairman JACOBS. If you can cram three into one, that will be fine.

Mr. MEEK. Fine, and we will be very brief.

We are pleased to appear this morning for formal congressional consideration of hospice legislation.

We represent the majority of the community-based care provided in this country and we strongly support expansion of hospice care that would be accomplished by H.R. 5180.

However, as with any legislative proposal, there are a number of questions which we and others will want to see addressed. Raising these issues should not obscure our commitment to community-based care for the terminally ill.

We think that: (1) the hospice patient and his or her family should have access to counseling and support services that are especially suited to their problems; (2) hospice care should be integrated into the existing health care system in the community; and (3) that hospice coverage should discourage institutionalization and avoid structural requirements for providers that would be inefficient and costly.

We believe that the range of covered services in the bill is highly desirable. The coverage of bereavement and other counseling is especially important in focusing on the circumstances of a specific patient and his or her family.

One question that presents itself is the degree to which curative services are covered in the hospice benefit. Because hospice coverage is justified as a substitute for curative services, it may be useful to explore appropriate limitations on these services without attempting to deny a terminally ill patient any service that may be supportive and palliative. The definitions of what is supportive and palliative will be very important.

Next, we think that the status of hospice programs as separate providers, should be closely examined to assure that hospice care is integrated as far as feasible into the health care structure. Any arrangement that might lead to removing hospice programs from close interrelationships with other community services should be approached with great caution.

We would want to make sure that existing community resources in home health agencies and elsewhere are fully utilized and not duplicated or syphoned off by hospice programs.

The 3,000 medicare-certified home health agencies alone contain resources which could be brought into even greater service to terminally ill patients if they are, in fact, available and trained to provide hospice care, either directly or indirectly. In this regard, existing criteria for quality assurance, for nursing, aid, therapy and other services, should be utilized wherever applicable to avoid unnecessary effort and duplication.

In addition, we specifically object to the bill's requirement that services, if provided under arrangement, may be provided only under arrangment with another hospice program. Alternatives to

this limitation must be explored so that hospice care can be efficiently provided by utilizing of properly qualified existing community resources wherever possible. In fact, this is how some hospice programs now operate and so long as accountability is maintained, there is no reason to discontinue this useful practice.

Although many cost questions will be discussed as the bill moves through the Congress, H.R. 5180 would provide an important new tool for avoiding the cost of undesirable and inappropriate institutional care. As we in community-based care have known for years, services in the home can help to reduce costs by replacing care that otherwise would be available only in a hospital or nursing home. The 75-percent cap and the effort to limit impatient days are additional provisions that may work toward assuring that hospice benefit will be cost-effective.

All these questions and others that are sure to arise as the discussion continues should not obscure certain essential facts. The sponsors and supporters of H.R. 5180 are to be congratulated for moving community-based hospice care to the active agenda of the Congress. As with any proposal of this importance, there are bound to be questions to be addressed as the bill is considered by you in the committee.

The home health provider community believes that home health care services can be and should be the backbone of hospice programs. We urge you to move ahead to resolve the issues we have raised today and to confirm community-based hospice care as a full partner in our national health care program.

We look forward to cooperating with you and your staff as you move forward with this bill.

Thank you, Mr. Chairman.

[The prepared statement follows:]

STATEMENT OF PETER MEEK, ON BEHALF OF THE HOME HEALTH SERVICES AND STAFFING ASSOCIATION, NATIONAL ASSOCIATION FOR HOME CARE, NATIONAL HOMECARING COUNCIL

Mr. Chairman and Members of the Subcommittee: I am Peter Meek, representing the National HomeCaring Council. With me this morning are Elizabeth Davis, Secretary of the National Association for Home Care (NAHC), and Patricia Page, Vice Chairman of the Home Health Services and Staffing Association (HHSSA).

Our three organizations join in the statement that I will present. However, with your permission, Mr. Chairman, each of us would like to reserve the opportunity to submit further information for your hearing record.

For the Subcommittee's information, the National HomeCaring Council is a national standards-setting organization especially concerned with the paraprofessional component of in-home care, the homemaker-home health aide. HHSSA represents multi-state for-profit providers of home health care. NAHC is the new national organization resulting from a merger of the National Association of Home Health Agencies and certain home health activities of the National League for Nursing.

We are pleased, Mr. Chairman, to appear this morning as formal Congressional consideration of hospice legislation begins. Because we represent the majority of the community-based care provided in this country, we strongly support the expansion of hospice care that would be accomplished by H.R. 5180, the bill before you. As with any legislative proposal, there are a number of questions which we and others will want to address. But raising these issues should not obscure our commitment to community-based care for terminally ill patients.

I. INTRODUCTION

Let me state three principles which must characterize all community-based services.

First, they should focus on the individual patient and his or her family.

Second, community-based services should be a part of the continuum of care. Fragmentation among health care services and providers should be avoided.

Third, cost-effectiveness, always a concern, must be a chief objective these days.

Our members are already actively involved in providing care to terminally ill patients. In fact, some hospice programs are medicare-certified home health agencies. Home health agencies provide nursing and other care to Medicare beneficiaries who are terminally ill, directly through their own staffs and under contract to hospice programs. From this wealth of experience, we have come to believe strongly in the properiety and efficacy of community-based services for terminally ill patients.

Therefore, applying the three principles I just mentioned to the care of dying patients, we think that:

(1) The hospice patient and his or her family should have access to counseling and support services that are especially suited to their problems.

(2) Hospice care should be integrated into the existing health care system in the community.

(3) Hospice coverage should discourage institutionalization and avoid structural requirements for providers that would be inefficient and costly.

## II. COMMENTS ON H.R. 5180

### *A. Brief summary of the bill*

H.R. 5180 would provide coverage of hospice services under Medicare. Some of the requirements for a hospice program (Section 4 of the bill) are similar, if not identical, to the Medicare definition of home health services (Section 1861(m) of the Social Security Act). The major differences are:

First, the limitations that nursing and home health aide services be part-time or intermittent are removed for hospice programs.

Second, drugs and biologicals are covered.

Third, homemaker services, physicians services, short-term inpatient care and counseling are covered.

Fourth, 24-hour care and services of nurses, home health aides and homemakers are covered during periods of crisis and as necessary to maintain the patient at home.

In other respects, H.R. 5180 provides the same care and services as the existing Medicare home health services benefit: nursing, physical, occupational or speech therapy; medical social services, home health aides, and medical supplies and appliances.

H.R. 5180 also would not include a homebound requirement nor a qualification that hospice programs be primarily engaged in providing skilled nursing services. The bill would seek to limit the utilization of inpatient care by assurances that not more than 20% of aggregate days are inpatient days. The hospice program must have an inter-disciplinary group which provides care and establishes policies, and it must utilize volunteers in providing care. Payments for hospice services are limited, by means of a cap, to 75% of the regional cost of providing care to terminally ill cancer patients and by a requirement for volunteer services, as well as by the attempt to limit inpatient hospital care.

Mr. Chairman, measuring H.R. 5180 against the three principles I noted earlier, we have the following observations about the bill.

### *B. Range of covered services*

We believe that the range of covered services is highly desirable. The coverage of bereavement and other counseling is especially important in focussing on the circumstances of a specific patient and his or her family.

One question that presents itself is the degree to which curative services are covered in the hospice benefit. Because hospice coverage is justified as a substitute for curative services, it may be useful to explore appropriate limitations on these services, without attempting to deny a terminally ill patient any service that may be supportive and palliative. The definitions of what is "supportive" and "palliative" will be very important.

### *C. Separate provider status*

Next, Mr. Chairman, we think that the status of hospice programs as separate providers should be closely examined to assure that hospice care is integrated as far as feasible into the health care structure. Any arrangement that might lead to removing hospice programs from close interrelationships with other community services should be approached with great caution.

Separate provider status might serve desirable goals. Accountability is one that is often cited, but there may be other ways to achieve accountability and at the same time avoid the risks of fragmenting community services. We think that alternatives to separate provider status should be explored because there are important reasons not to confine terminally ill patients to receiving care from one specific type of provider.

For one thing, we wonder whether it is wise from society's point of view to confine the skills and capacities relevant to caring for dying persons to a specific type of organization. The hospice movement has contributed immeasurably to advancing dignified and thoughtful attention to the difficulties facing the dying and their families. The special capacities and training which the hospice movement has so effectively nurtured should become more typical of a wider variety of providers, both individual and institutional, who deal with chronic or gravely ill patients.

In the second place, we do not yet know enough about the various ways to structure care for the terminally ill to be able to say that we now know exactly how to structure hospice provider status. It is clear that there is wide variety in the types of hospice organizations, just as there is in other segments of the home health area. We think that there might well be a way to reflect this diversity without sacrificing the training and skills appropriate to care of the terminally ill and without diluting fiscal accountability.

Finally, we would want to make sure that existing community resources, in home health agencies and elsewhere, are fully utilized and not duplicated or siphoned off by hospice programs. The 3000 Medicare-certified home health agencies alone contain resources which could be brought into even greater service to terminally ill patients, if they are in fact available and trained to provide hospice care, either directly or indirectly. In this regard, existing criteria for quality assurance for nursing, aide, therapy and other services should be utilized wherever applicable to avoid unnecessary effort and duplication.

In addition, we specifically object to the bill's requirement that services, if provided under arrangement, may be provided only under arrangement with another hospice program. Alternatives to this limitation must be explored so that hospice care can be efficiently provided by utilizing properly qualified, existing community resources wherever possible. In fact, this is how many hospice programs now operate and, so long as accountability is maintained, there is no reason to discontinue this useful practice.

*D. Cost questions*

Although many cost questions will be discussed as the bill moves through the Congress, H.R. 5180 would provide an important new tool for avoiding the cost of undesirable and inappropriate institutional care. As we in community-based care have known for years, services in the home can help to reduce costs by replacing care that otherwise would be available only in a hospital or nursing home. The 75% cap and the effort to limit inpatient days are additional provisions that may work toward assuring that the hospice benefit will be cost-effective.

Among the cost-related questions we will want to see subsequently explored are:

(1) Will the 75% cap on payments result in providers being asked to provide services at less than their cost?

(2) How serious is the cost impact on the provider and on the Medicare program of the requirement that hospice programs provide care without regard to the beneficiary's ability to pay? Would the requirement mean that Medicare coinsurance, if any, could not be collected? Would the requirement extend to non-Medicare patients?

(3) How will determinations of providers' costs be affected by the definition of allowable costs as "costs which are reasonable and related to the cost necessary in the efficient delivery of hospice care"?

(4) How can the 20% limit on inpatient days be enforced? What can the sanctions be when that limit is exceeded if, as we must assume, the inpatient care was needed by the patient or, in the case of respite care, by his family?

(5) How will hospice providers show that volunteer services have resulted in cost savings and service expansion, as the bill requires? Will the associated record-keeping be a reimbursable cost? Are there any legal ramifications of providing care with volunteers?

(6) What is the relevance of data from the twenty-six Medicare hospice demonstration projects? What do their results show and how far can those data be taken in telling us what will happen if the bill is adopted? Is there anything to be said for initiating hospice coverage with the same limitation as the demonstrations, i.e., that services are available where there is a primary care provider?

III. CONCLUSION

All these questions—and others that are sure to arise as discussion continues—should not obscure certain essential facts. The sponsors and supporters of H.R. 5180 are to be congratulated for moving community-based hospice care to the active agenda of the Congress. As with any proposal of this importance, there are bound to be questions to be addressed as the bill is considered by you and your committee. There is no point in denying them. But there is also no point in saying that, simply because they exist, the objective is not a worthy one or that the present or future role of hospice care is not highly promising.

The home health provider community believes that home health care services can be and should be the backbone of hospice programs. We urge you to move ahead to resolve the issues we have raised today and to confirm community-based hospice care as a full partner in our national health care system. We look forward to cooperating actively with your staff and other interested parties as work on the bill goes forward.

Thank you.

Chairman JACOBS. Mr. Duncan.

Mr. DUNCAN. I have no particular questions. We usually find that the last sometimes is the best testimony we have and yours has been very good and very helpful.

We want to thank you and your Council for the study they have given and the help we will be needing from you in the future.

Thank you.

Mr. MEEK. Thank you.

Chairman JACOBS. I should say also, the subcommittee is grateful for the consolidation of the testimony. It is concise and, as Mr. Duncan has said, it is very useful to the committee.

Ms. DAVIS. Mr. Chairman, may I amplify just one point Mr. Meek has made?

I am Betsy Davis, as was mentioned, secretary of the National Association for Home Care. In addition, I am executive director of the Visiting Nurse Association, located in northwestern Vermont.

Our agency is also one of the 26 HCFA hospice demonstration programs serving along with four other home health agencies, the entire northern section of the State of Vermont.

There is just one point in Mr. Meek's presentation which I do wish to amplify, that is, that hospice can be integrated into the existing health care system in the community. Our experience in Vermont, I think, has well demonstrated that fact.

Yet we also emphasize the importance of a well-defined hospice program, the need for extra training and ongoing staff development and the need for separate cost accounting and evaluation.

This we feel has been accomplished in our experience. We have data available demonstrating both the cost-effectiveness of hospice care and, as well, the tremendous family and client satisfaction in having a choice in managing the last days of life.

Blue Cross in our State has also participated in the demonstration, and recently has made the decision, based on their experience, to continue the demonstration, and to extend it statewide.

The National Association for Home Care supports this legislaton and trusts that the questions raised by Mr. Meek can be quickly resolved in order to continue to move this important legislation through Congress.

We thank you for bringing this important legislation out as an active agenda item.

Chairman JACOBS. Thank you, Ms. Davis, for your contribution.

You are dismissed with our gratitude. Thank you.

Is the Connecticut delegation here or are they still fogbound?

Well, let the record show, then, that their statement will be included in the record, of course.

[The statement of Connecticut Hospice, Inc., follows:]

The Connecticut hospice Inc.

61 Burban Drive
Branford, Connecticut 06405

*serving connecticut and the nation*

**General Offices** (203) 481-6231
**Home Care** (203) 481-6201
**In-Patient** (203) 481-6261

TESTIMONY

of

THE CONNECTICUT HOSPICE, INC.

on

H.R. 5180-S 1958

**Board of Directors** - Frederick D. Grave, Jr., *President* - Elinor N. Hansen, *First Vice President* - Arlene M. Sayers, *Second Vice President* - Charles J. Mills, *Secretary* - Robert L. Gary, *Treasurer* - Claire Baird - Attorney Thomas Birmingham - Rt. Rev. John M. Burgess - Carole J. Donovan - Denis Evans - Richard Farricker - Marlin D. Gahner, Jr. - Robert H. Gifford, M.D. - Honorable Lucy T. Hammer - Edward Lapides - Honorable Herbert S. MacDonald - Edward W. Miller - Carmella V. Piacentini - Mildred Pierce - Richard Root, M.D. - William Simpson - Hubert L. Smith, M.D. - Honorable Dennis J. Spain - Samuel O. Thier, M.D. - John D. Thompson - Claudia H. Warner - **Administrator** - Rosemary Johnson-Hürzeler

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PREFACE

All of us who believe in furthering the delivery of hospice care in the United States realize that federal support is the key to assuring that hospice care is accessible to patients and financially feasible for providers. Hospice care, when available as an alternative, can save considerable Medicare expenditures for care of the terminally ill. Because of the significant cost savings which could be realized, and since 74 % of our patients requiring that care are Medicare eligible, hospice care should be reimbursed by Medicare. However, the present construction of this proposed legislation is flawed in achieving the goal of making hospice care available as a less costly alternative to traditional modes of care for patients with a terminal illness.

We respectfully suggest the following changes to H.R. 5180-S. 1958:

1. In order to contain the costs of this service, we propose the substitution of a prospectively negotiated, cost-based reimbursement system as the cost control mechanism, rather than the utilization of a cap methodology, to control spending.

2. Change the aggregate allowable ratio of inpatient days to home care days from 20:80 to 50:50. This means that if patients need more inpatient days, they may receive them; it also allows a higher percentage of inpatient care for those patients who reside outside of the geographic area served by the hospice home care program.

3. Include quality standards for accreditation which are based on the standards for hospice care now being developed by the Joint Commission for the Accreditation of Hospitals. Include a more precise statement of quality standards, such as separate state licensure regulation as a "hospice" and minimum daily census requirements (combined home care and inpatient count) in order to support the minimum mix of services required to offer quality care.

4. Require evidence of non-discriminatory practices in the selection of patients to assure that patients are accepted on the basis of medical need, without regard to potentially prejudicial factors such as life expectancy or source of reimbursement.

We will now address these recommendations in the light of our experience.

## ANALYSIS OF PATIENT SERVICE DATA AT THE CONNECTICUT HOSPICE

The Connecticut Hospice is the nation's oldest Hospice, and one of the nation's largest. Incorporated in 1971, it currently serves over 50% of the dying cancer patients in its service area (See Appendix I for an organizational profile). The Connecticut Hospice submits this testimony after extensive analysis of its own computerized, patient care database, which includes almost two full years of Hospice inpatient and home care services.

This analysis was performed to achieve three goals:

1. To calculate the average expense of caring for each Hospice patient from the time of the first Hospice admission until the patient is finally discharged or deceased;
2. To document the mix of Hospice services which are required to care for dying patients when services are prescribed freely by care providers who are unfettered by regulatory requirements or reimbursement limits; and
3. To estimate the savings in reimbursement dollars and the improvements in quality and appropriateness of care resulting from the availability of inpatient and home hospice care in Connecticut.

The following tables and descriptions document the results of our study. As the analysis demonstrates, Hospice services are cost-effective, and hospices meet the current demand for specialized care of terminally ill patients and their families. We feel it is critical that the proposed hospice reimbursement legislation be restructured to include the changes we are suggesting. We present the following data in support of these suggestions.

### 1. CALCULATION OF SERVICE MIX AND AVERAGE PATIENT EXPENSE

To calculate the average cost per patient of Hospice care, all patients receiving any care during Fiscal Year 1981 and who were deceased at the time of the study were analyzed. These 681 patients were selected for study on the basis that their hospice continuum of care had concluded, except that in some cases bereavement care continues to be provided.

All inpatient and home care services provided to these patients during their entire Hospice care period were analyzed. The results of the analysis are summarized below, and illustrated in Table 1.

- The average Hospice patient remained within the hospice care system for 35 days; this care is distributed equally between inpatient and home care services.

- The cost of providing Hospice care to those patients averaged $6,033 per patient. The median expense for those patients was $2800. The average expense was increased considerably by patients who experienced extremely long inpatient stays due to unpredictable and unavoidable complications with their care and the progression of illness (see Figure A). The average expense was also increased by those patients who reside outside the home care service area and who therefore receive only inpatient services.

- 5% of hospice inpatients and 31% of Hospice home care patients were referred to an acute care hospital for care during their total Hospice episode of care. The average length of stay for those hospitalizations was 11 days. These hospitalizations were medically indicated, and were fearfully expensive.

Table 1 - COST ANALYSIS OF HOSPICE CARE
BY SEQUENCE AND NUMBER OF PATIENT ADMISSIONS
CONNECTICUT HOSPICE - FISCAL YEAR 1981

This table presents the average inpatient and home care days, and the average total expense of Hospice care, for each patient/episode combination. For Home Care expense, costs for pharmaceuticals, equipment, medical supplies, physical and other therapies, X-ray, and laboratory services are excluded.

| EPISODE COMBINATION | NUMBER OF PATIENTS | CUM. % | AVERAGE # OF DAYS: INPATIENT | HOME CARE | AVERAGE TOTAL COST |
|---|---|---|---|---|---|
| 1 Inpatient episode only (1) | 385 (56%) | 56% | 26 | 0 | $7,395 |
| 1 Home Care episode only | 116 (17%) | 73% | 0 | 32 | $1,255 |
| 1 Home Care & 1 Inpatient episode | 123 (18%) | 91% | 11 | 38 | $4,315 |
| 2 Inpatient episodes only (1) | 11 (2%) | 93% | 62 | 0 | $17,618 |
| 2 Home Care episodes only | 11 (2%) | 95% | 0 | 79 | $1,856 |
| 3 Episodes, any combination | 15 (2%) | 97% | 21 | 81 | $8,690 |
| 4 Episodes, any combination | 15 (2%) | 99% | 36 | 81 | $12,795 |
| 5 Episodes, any combination | 2 (*) | 99% | 15 | 96 | $7,186 |
| 6 Episodes, any type | 2 (*) | 100% | 54 | 71 | $18,926 |
| ALL PATIENTS: | 681 | 100% | 18 | 17 | $6,033 |

(*) Less than one percent
(1) Since the Connecticut Hospice is the only such inpatient institution in the state, many of these cases were referred from out of its primary service area, increasing the average costs in these categories.

2. REIMBURSEMENT SAVINGS AND IMPROVED QUALITY OF CARE

HOME CARE:

Area physicians prescribed 11,183 days of hospice home care services to the patients receiving care at the Connecticut Hospice in Fiscal Year 1981. If hospice home care services were not available, some portion of those patients would have been hospitalized or institutionalized, and the remaining majority of those patients would have been placed under local visiting nurse care. Although visiting nurse associations provide excellent home care for a variety of illnesses, home care provided by the trained hospice team is a more appropriate form of care for terminally ill patients who are able to remain at home. This care can be provided either as an independent hospice service or as a hospice component of a visiting nurse association.

The cost of providing home care to hospice patients averages $36 per day. This cost is comparable to the cost of providing home agency nursing care; however, the terminally ill patients are receiving more appropriate care than they would otherwise have received if no hospice home care program were available. For those patients who would have required hospitalization if the hospice home care services were not available, the hospice program allowed a savings of over $300 per day.

HOSPICE HOME CARE - FISCAL YEAR 1981

| # PATIENTS RECEIVING HOME CARE SERVICES | HOME CARE * PATIENT DAYS | AVERAGE # DAYS PER PATIENT | AVERAGE COST: PER DAY | AVERAGE COST: PER PATIENT |
|---|---|---|---|---|
| 285 | 11,183 | 39 | $36.00 | $1,400 |

* Home Care patient days represent days during which the patient was under the supervision of the Hospice Home Care Team; patients received those services deemed necessary by the team-derived treatment plan.

INPATIENT CARE:

The availability of inpatient hospice care in Connecticut has allowed area physicians to prescribe inpatient care for the terminally ill at the lower per-diem hospice rates, rather than in local acute-care facilities at higher rates. The per diem charge for Hospice inpatient care at the Connecticut Hospice is currently $285.00; this rate is all-inclusive, so that no extra ancillary or service charges are added to any patient bills. The average per-diem reimbursement rate for Medical and Surgical admissions to those acute-care hospitals serving the same area as the Connecticut Hospice is approximately $370; this average includes estimates of ancillary charges each day.

If inpatient hospice care is available, each inpatient hospice day of care which is substituted for an inpatient day in an acute care setting saves an average of $85. This savings is realized despite the fact that the inpatient Hospice unit is staffed with nurses at approximately the intensive care unit level, and is equipped to provide more appropriate care than hospitals for those terminally ill patients requiring inpatient care than are hospitals.

The Connecticut Hospice inpatient unit provided 12,013 inpatient days of care to those patients receiving Hospice care during fiscal year 1981. The reasons for inpatient hospice admission of a ten percent random sample of those patients were analyzed. Based on this study, we have concluded that in almost every case, those patients requiring inpatient hospice care would have been hospitalized at local acute-care hospitals if the Connecticut Hospice inpatient facility were not available.

Therefore, in providing the 12,013 days of inpatient care to the 554 patients receiving inpatient care during the year, the Connecticut Hospice not only provided more appropriate care for those patients than they would have received in the acute care setting, but also allowed a savings of approximately $1,022,000.

INPATIENT CARE SAVINGS - FISCAL YEAR 1981

| NUMBER OF PATIENTS | NUMBER OF INPATIENT DAYS | COST AT HOSPICE | COST AT ACUTE-CARE | ESTIMATED SAVINGS |
|---|---|---|---|---|
| 554 | 12,013 | $3,424,275 | $4,445,550 | $1,021,275 |

Currently, 74% of the Connecticut Hospice inpatient population is Medicare eligible. Therefore, in Fiscal Year 1981 alone, the estimated savings to the Medicare system by the availability of Hospice inpatient care was approximately $750,000.

PROPOSED REVISIONS TO LEGISLATION

1. IN ORDER TO CONTAIN THE COSTS OF THIS SERVICE, WE PROPOSE THE SUBSTITUTION OF A PROSPECTIVELY NEGOTIATED, COST-BASED REIMBURSEMENT SYSTEM AS THE COST CONTROL MECHANISM, RATHER THAN THE UTILIZATION OF A CAP OR CEILING METHODOLOGY, TO CONTROL SPENDING.

Given the inflationary effect of retrospective cost based reimbursement, we propose that the hospice providers, under this legislation, receive a prospectively negotiated reimbursement rate in lieu of cost-based reimbursement with a ceiling. In this way, controlled costs would be based on services received by hospice patients, not on some estimate of 75% of fees historically paid for patients who never received hospice care.

Under the system outlined in the bill, the provider must carefully control the number of care days and/or units of service provided so that the year-end Medicare payment adequately covers the costs incurred for all patient care. This method of reimbursement forces the financially prudent hospice provider to be constantly vigilant of the presumed life expectancy of any patient referred into the hospice program of care before accepting that patient for care.

Figure A demonstrates the importance of the distribution of patient expense. The percentage of patients who experience extremely high costs causes the <u>average</u> patient cost to be significantly above the median cost.

Applied to a population of Hospice providers striving to maintain financial viability the reimbursement structure encourages the Hospice provider to allow the potential patient to remain within the traditional Medicare-reimbursable care system until the patient's life expectancy is short. In this way the provider minimizes the risk of having to care for the significant percentage of high cost patients described in Figure A. The predictable effect of this legislation, as currently written, will be to create an <u>add-on</u> to current Medicare expenditures for the terminally ill, and lessen the total impact of the hospice program.

The current structure of H.R. 5180-S. 1958 creates a disincentive to substitute hospice care for more traditional and more expensive care early in the course of the illness. The legislation operates as a direct incentive to maximize the use of the non-hospice care system, thereby maximizing use of routine Medicare benefits, before tapping the hospice benefit. Incentives are needed to encourage health care providers to offer and promote hospice care as a less costly and more appropriate method of caring for the terminally ill patient/family.

Hospice care has been based on maintaining rigorous quality of care standards for a period of time limited by the nature of the patient's illness. The care of the terminally ill should not be restructured to fit into artificial reimbursement policies. The reimbursement mechanism in the pruposed legislation should be revised to encourage the use of Hospice care as an <u>alternative</u> to more traditional forms of care, and to allow care providers to tailor that care to meet the needs of the patients, not the reimbursement system.

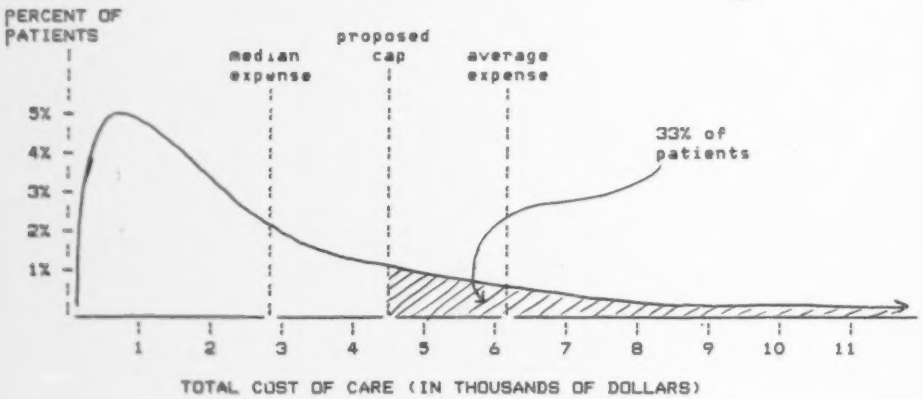
Prospective reimbursement will require each hospice provider to forecast its expenses and revenues for the budget year. The rates established as a result of these negotiations would be subject to revision or rejection by the reimbursers for failure to meet tests for "reasonableness" before services were provided, not after. Each hospice would project and justify all expenses involved in patient care in the course of extensive review and revision by the appropriate regulatory agencies. Upon agreement to prospective rates, the hospice provider would be required to operate within its expense projections for the year.

The cost controls imposed by the prospective reimbursement methodology are equally as effective as the cap method, yet do not adulterate the quality of the care received by the terminally ill patient. The emphasis on cost efficiency remains yet the hospice provider can continue to make patient need, rather than financial prudence, its priority.

<u>Figure A</u>

DISTRIBUTION OF TOTAL COST OF HOSPICE CARE PER PATIENT

CONNECTICUT HOSPICE - FISCAL YEAR 1981



2. CHANGE THE AGGREGATE ALLOWABLE RATIO OF INPATIENT TO HOME CARE DAYS FROM 20:80 TO 50:50. THIS MEANS THAT IF PATIENTS NEED MORE INPATIENT DAYS, THEY MAY RECEIVE THEM; IT ALSO ALLOWS A HIGHER PERCENTAGE OF INPATIENT CARE DAYS FOR THOSE PATIENTS WHO RESIDE OUTSIDE OF THE GEOGRAPHICAL AREA SERVED BY THE HOSPICE HOME CARE TEAM.

The proposed legislation contains the requirement that no patient receive more than 20% of their care days in an inpatient setting after that patient is accepted into the hospice system. The experience of the Connecticut Hospice indicates that this requirement is unrealistic. As documented in Table 2, physicians in Connecticut have prescribed inpatient hospice care days for their patients which comprise 50% of all care days (home care and inpatient) provided by The Connecticut Hospice in Fiscal Year 1981. For patients residing within the geographical area served by the Connecticut hospice home care program, 40% of their care days were in the inpatient unit. Patients outside the primary service area received only inpatient care at the Connecticut Hospice because those patients resided outside the geographical boundaries of the Connecticut Hospice Home Care program.

The mix of Hosice inpatient and home care days experienced by the sample group was directed by physicians and care providers whose only consideration was the optimal care of each patient. No regulatory or reimbursement limitations were imposed on these providers, so the resulting care patterns provide an accurate picture of the hospice home care and hospice inpatient care required by dying patients.

Based on these results, we recommend that H.R.5180 - S. 1958 be altered to allow a 50:50 ratio of home care to inpatient days with exceptions made for patients who reside outside of the primary service area of the hospice.

Table 2

INPATIENT AND HOME CARE DAYS
FOR PATIENTS IN AND OUT OF
PRIMARY HOSPICE SERVICE AREA *

| PATIENT GROUP | NUMBER OF PATIENTS | AVERAGE NUMBER OF DAYS OF CARE: INPATIENT | HOME CARE | TOTAL | RATIO OF INPATIENT TO HOME CARE DAY |
|---|---|---|---|---|---|
| In service area | 496 (73%) | 16 | 24 | 40 | 40:60 |
| Outside service area | 185 (27%) | 27 | 0 | 27 | 100:00 |
| Total | 681 (100%) | 18 | 17 | 35 | 52:48 |

* Comprehensive hospice home care and inpatient services are available to residents of the 18 cities and towns within a 50-mile radius of New Haven, Connecticut -- this geographical area (Health Services Area II) is the primary service area of The Connecticut Hospice. The Connecticut Hospice inpatient facility services all Connecticut residents.

3. INCLUDE QUALITY STANDARDS FOR ACCREDITATION WHICH ARE BASED ON THE STANDARDS FOR HOSPICE CARE NOW BEING DEVELOPED BY THE JOINT COMMISSION FOR THE ACCREDITATION OF HOSPITALS. INCLUDE A MORE PRECISE STATEMENT OF QUALITY STANDARDS, SUCH AS SEPARATE STATE LICENSURE REGULATION AS A "HOSPICE", AND MINIMUM DAILY CENSUS REQUIREMENTS (COMBINED HOME CARE AND INPATIENT COUNT) IN ORDER TO SUPPORT THE MINIMUM MIX OF SERVICES REQUIRED TO OFFER QUALITY CARE.

The proposed legislation is vague with regard to requirements for accreditation of Hospice programs. The State of Connecticut was the first state to create a licensure category for a Short Term Hospital, Special-Hospice in its Public Health Code, Section 19-13 D4b (See Appendix 2). All cost data for the Connecticut Hospice is dictated by compliance with Connecticut licensure requirements. Until hospice care standards, accreditation or licensure regulations are established, the equitable administration of Medicare funds cannot be achieved. The consumer is at considerable risk when no certifying, licensing, or accreditation process protects their interests in quality Hospice care. This risk extends to the patient families, the Social Security trust funds, the care providers, and the taxpayer.

The proposed legislation must include quality standards for accreditation which use Joint Commission on Accreditation of Hospitals baseline standards.

4. REQUIRE EVIDENCE OF NON-DISCRIMINATORY PRACTICES IN THE SELECTION OF PATIENTS TO ASSURE THAT PATIENTS ARE ACCEPTED ON THE BASIS OF MEDICAL NEED, WITHOUT REGARD TO POTENTIALLY PREJUDICIAL FACTORS SUCH AS LIFE EXPECTANCY OR SOURCE OF REIMBURSEMENT.

To obtain Medicare certification, all hospice providers should be required to submit evidence of non-discriminatory admissions policies. Regardless of the reimbursement mechanism used for hospice care, it will always be possible for administrators to favorably affect the financial position of a "hospice" by altering admissions policies to exclude those patients who might create a financial drain on the program. Primary targets for exclusion would be those patients who are not Medicare or Medicaid eligible and who have no or limited insurance coverage, and those patients whose life expectancy or expected service needs exceed pre-determined reimbursement limits. We therefore suggest that the proposed legislation be amended to include a requirement of evidence on non-discriminatory admissions standards, not only with regard to sex, race, or religion, but primarily with regard to life expectancy and reimbursement source.

Appendix 1

PROFILE

THE CONNECTICUT HOSPICE, INC.
Incorporated 1971
Non-Profit 501 (c) (3)

| | |
|---|---|
| Components: | 44 beds inpatient - serves the State of Connecticut<br>Home Care - serves 18 cities and towns in Health services area II<br>Bereavement - serves the State of Connecticut |
| License: | Short-term [illegible] special, Hospice<br>State of Connecticut Public Health Code 19-13-D4b |
| Medicare Certification: | Home Health Agency, Hospital |
| Hospice Classification: | Free-standing facility<br>Charter and voting member, National Hospice Organization |
| Paid Staff: | 190 persons, 151 full-time equivalents |
| Volunteers: | 275 persons (250 donating 4 hours per week) |
| Closed panel of physicians: | To achieve consistency of appropriate and specialized care |
| Prospective Budget Approval: | Commission on Hospitals and Health Care |
| Reimbursement: | All major third party payors, and HCFA demonstration |
| Population Served: | 51% of all dying patients in service area.<br>480 individual physicians each year select hospice as the appropriate mode of care for this patient population. |
| Annual Caseload: | 737 individual patients; 970 different admissions |
| Annual Budget: | $4,500,000 |
| Certified Public Accountant: | Ernst & Winney - Frank Elmer, Partner |
| Legal Counsel: | Wiggin & Dana - John Q. Tilson, Partner |

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## APPENDIX 2:

## STATE OF CONNECTICUT PUBLIC HEALTH CODE SECTION 19-13-D4b HOSPICE LICENSURE



tc the emergency system shall either be connected through the above described primary automatic transfer switches or through other automatic or manual transfer switches. Receptacles connected to the emergency system shall be distinctively marked. Storage-battery-powered lights, provided to augment the emergency lighting or for continuity of lighting during the interim of transfer switching immediately following an interruption of the normal service supply, shall not be used as a substitute for the requirement of a generator. Where stored fuel is required for emergency generator operation, the storage capacity shall be sufficient for not less than forty-eight hour continuous operation. When the generator is operated by fuel which is normally piped underground to the site from a utility distribution system, fuel storage facilities on the site will not be required.

11. Maintenance of systems and equipment. All electrical, gas, life safety, life support and critical systems shall be tested to insure satisfactory performance prior to placing them into service and tested annually thereafter. Permanent records of all tests shall be maintained.

(b) **Administration:** (1) The hospice shall be managed by a governing board with full legal authority and responsibility for the conduct of the hospice and the quality of medical care provided at the facility. Duties of the governing board shall include, as a minimum:

(A) Adoption of the following in writing and upon adoption enforcing compliance with:

(1) admission criteria defining eligibility for hospice services;

(2) guidelines for community relations;

(3) a patient bill of rights;

(4) medical by-laws after considering the recommendations, if any, of the medical staff;

(5) rules and by-laws which include the following:

(a) the purpose of the hospice;

(b) annual review of the rules and by-laws which shall be dated and signed by the chairman of the board;

(c) the powers and duties of the officers and committees of the governing body; (d) the qualifications, method of selection and terms of office of members and chairmen of committees;

(e) a mechanism for approval of the appointments to the medical staff;

(f) qualifications for appointment to the medical staff based upon background, competence, adherence to the ethics of the profession and physical and mental status;

(g) a schedule of at least ten (10) regular meetings per calendar year;

(h) a specific policy governing conflict of interest of members.

(B) Establishment of a joint practice committee composed of representatives of medical staff, nursing staff, pharmacy staff, social work staff, arts and pastoral care staff, volunteer staff and the administrator or designee.

(C) Appointment of the administrator who shall have one of the following:

(1) completed postgraduate training approved by the Association of University Programs in hospital administration;

(2) attained three years experience as an assistant administrator;

(3) served three years as a hospital administrator under a state approved hospice program;

(4) qualified by other experience approved by the state department of health services upon written application to the commissioner.

(2) The administrator shall be responsible to the governing board for the management and operation of the hospice and for the employment of personnel. He shall attend meetings of the governing board and of the medical staff, employ personnel of good character and suitable temperament in sufficient numbers to provide satisfactory care for the patients.

(3) Outside services or resources as required by the facility or ordered by the physician shall be utilized only pursuant to written agreements. The responsibilities, function and terms of each agreement, including financial arrangements and charges, shall be specified therein and signed and dated by the chairman of the board, or administrator of the hospice and the person or duly authorized official of the agency providing the service or resource.

(4) Any person or his family may request hospice in-patient, out-patient and hospice-based home care services with the concurrence of a member of the medical staff of the facility.

(c) **Medical staff:** (1) There shall be a medical staff of not fewer than five physicians, one of whom shall serve as a chief, president, or medical director of the medical staff and all of whom shall be licensed to practice medicine and surgery in Connecticut. The medical staff shall be composed of active medical staff, associate medical staff, courtesy medical staff, consulting medical staff and honorary medical staff.

(2) The medical staff shall adopt written by-laws and rules governing its own activities not inconsistent with any rule, regulation, or policy of the governing board, which by-laws and rules shall not become effective until approved by the governing board and shall be subject to recession by the governing board, which shall include:

(A) requirements for admission to staff and for the delineation and retention of clinical privileges;

(B) method of control of clinical work, including written consultations for all clinical services which shall be properly entered onto the patient's chart;

(C) analysis, review and evaluation of clinical practices within hospice in-patient, out-patient and hospice-based home care programs, to promote and maintain high quality care;

(D) a framework to insure twenty-four hour, seven-day-a-week on-call availability, including physician home visits, and eight-hour-a-day on-site medical staff coverage;

(E) provision for monthly staff conferences unless clinical groups hold departmental or service conferences at least monthly, then general staff conferences shall be held at least four times each year, and each active staff member shall attend a minimum of ten departmental or general staff meetings or a combination thereof each year;

(F) establishment of committees including infection control, safety, quality assurance, pharmacy and therapeutics, medical record audit, patient care, and others as necessary;

(G) procedure for recommending appointments to the medical staff, hearing complaints regarding the conduct of members and referring the same, with recommendations, to the governing board.

(3) Any patient's primary care community physician who is not a member of the hospice medical staff may request hospice-provided services for the patient with the concurrence of a hospice medical staff member.

(4) Medical staff and departmental meetings must be attended by at least fifty percent of the active staff members to be counted toward the mandatory meeting quotas. Minutes and a record of attendance shall be kept.

(5) There shall be a department of medicine under the direction of a physician licensed to practice medicine and surgery in Connecticut, who shall be responsible for supervising the quality of medical service.

(6) The chief, president, or medical director of the medical staff shall supervise the bereavement team which shall consist of himself, a consulting psychiatrist and one representative from each of the following services: volunteer, pastoral care, arts, social work and nursing.

(7) The medical staff shall provide and participate in a continuing program of professional education which shall include hospice-based home care programs scheduled on a regular basis with appropriate documentation of these activities.

(d) Medical records: (1) There shall be a medical record department with adequate space, equipment and qualified personnel

including a medical record librarian or a person with training, experience and consultation from a medical record librarian.

(2) A medical record shall be maintained for every individual who is evaluated or treated as a hospice in-patient, out-patient or who received patient services in a hospice-based home care program.

(3) An in-patient record shall be started at the time of admission with identification, date, and a nurse's notation of condition on admission. To this shall be added immediately an admisson note and orders by the attending member of the active medical staff. A complete history and physical examination shall be recorded by a staff physician within twenty-four hours of admission, unless the patient is being followed by his primary physician who performed the patient's last history and physical examination within forty-eight hours and the referral to the hospice program is made within the same institution. A problem-oriented medical record shall be completed by the primary care nurse within twenty-four hours of admission.

(4) All medical records shall be prepared accurately and physicians' entries completed promptly with sufficient information and progress notes to justify the diagnosis and warrant the treatment and palliation. Doctors' orders, nurses' notes and notes from other disciplines, shall be kept current in a professional manner and all entries shall be signed with a legally acceptable signature by the person responsible for them.

(5) The medical records shall be kept confidential and secured. Written consent of the patient or his legally appointed representative shall be required for release of medical information except as provided in Section 19-13-D4b. (t).

(6) The records shall be filed and stored in a manner providing easy retrievability and shall be kept for a minimum of twenty-five years after discharge of patients, except that original medical records may be destroyed sooner if they are microfilmed by a process approved by the state department of health services.

(7) Completion of the medical records shall be accomplished within one day after discharge to a hospice-based home care program or within seven days of death.

(8) Persistent failure by a physician to maintain proper records of his patients, promptly prepared and completed, shall constitute grounds for suspending or withdrawing his medical staff privileges.

(e) Nursing Service: (1) The nursing service shall be directed by the director of hospice patient care services who shall be a registered nurse with baccalaureate degree in nursing and an active Connecticut license, and is further qualified by one of the following:

(A) a master's degree from a program approved by the National League of Nursing or the American Public Health Association with a minimum of two (2) years' full-time clinical experience under

qualified supervision, in a hospice or home health agency related community health program which included care of the sick;

(B) a minimum of four (4) years of full-time clinical experience in nursing, at least two (2) of which were under qualified supervision in a hospice or home health agency or community health program which included care of the sick;

(C) employment as a supervisor in a hospice or home health agency as of January 1, 1979, but effective January 1, 1982 no person shall be such supervisor who does not satisfy the requirements of subparagraphs (A) or (B) of this regulation.

(2) A registered nurse with a baccalaureate degree in nursing and an active Connecticut license and one of the following shall serve as a supervisor of hospice in-patient and hospice-based home care program under the direction of the director of hospice patient care services: (A) a master's degree from a program approved by the National League for Nursing or the American Public Health Association with a minimum of two (2) years' full-time clinical experience under qualified supervision, one of which shall be in a health care institution and one of which shall be in a hospice or home health agency or a related community health program.

(B) a minimum of four (4) years' full-time clinical experience in nursing under qualified supervision, one of which shall be in a health care institution and one of which shall be in a hospice or home health agency or related community health program.

(C) employment as a supervisor of clinical services in a hospice or home health agency as of January 1, 1979, but effective January 1, 1982 no person shall be such supervisor who does not satisfy the requirements of subparagraphs (A) or (B) of this regulation.

(3) The ratio of patients to registered nurses in the hospice shall not be less than one nurse to six patients per eight hour shift.

(4) The ratio of all nursing staff and nurses aides to patients shall not be less than one nurse or nurse aide to three patients.

(5) An organization plan of the nursing service shall be established which shall delineate its mechanism for cooperative planning and decision making.

(6) Written nursing care and administrative policies and procedures shall be developed to provide the nursing staff with practical methods of meeting its responsibilities and achieving projected goals. Policies shall include, but not be limited to, the following:

(A) assigning the nursing care of patients to a primary care provider who develops a written pertinent care plan;

(B) standardized procedures for evaluation and study;

(C) a program of systematic professional and administrative review and evaluation of the service's effectiveness in relation to stated objectives;

(D) patient and family teaching programs;

(E) the development and implementation of staffing patterns that will assure efficient performance of departmental activities;

(F) participation in the joint practice committee for the improvement of patient care including equal representation of practicing nurses and physicians, and continuous redefining of the scope of medical and nursing practice in the light of experience and patient care needs.

(7) There shall be staff development programs and educational opportunities for nursing personnel which include orientation and in-service education.

(f) **Pharmaceutical service:** (1) The institution shall maintain an organized pharmaceutical service that is conducted in accordance with current standards of practice and all applicable laws and regulations.

(2) The pharmaceutical service shall be directed by a licensed pharmacist trained in the specialized functions of an institutional pharmacy who shall serve the institution:

(A) on a full-time basis in a free-standing facility;

(B) in a distinct unit identified as hospice on a part-time basis consonant with the size and scope of services of the institution.

(3) The scope of pharmaceutical services shall be consistent with the drug therapy needs of the patients as determined by the medical staff.

(4) There shall be an active medical staff committee, composed of a physician, the director of pharmacy, the director of patient care services, and a representative from administration which shall serve in an advisory capacity to the professional staff on matters relating to drugs and drug practices. Specific functions of this committee, which shall meet at least quarterly, shall include:

(A) development of broad professional policies regarding the evaluation, selection, procurement, distribution, use, safe-practices and other matters pertinent to drugs in the institutions;

(B) development of basic formulary system of drugs for use in the institutions;

(C) monitoring and reporting adverse drug reactions in the institution, and introducing proper measures to minimize their incidence;

(D) reviewing and analyzing medication incidents in the institution and taking appropriate action to minimize the recurrence of such incidents;

(E) determining drug-use patterns and assisting in the setting of drug-use criteria relative to the institution's drug utilization review program.

(5) There shall be a current, written policy and procedures manual approved by the medical staff, pertaining to the drug control system in the institution.

(g) **Social work service:** (1) There shall be a written plan with clearly defined written policies governing the delivery of social work services in the hospice in-patient, out-patient and hospice-based home care program which shall include a procedure for reporting problem areas to the administrator, recommended solutions, and identify action taken. These policies shall incorporate the current standards, guidelines, and code of ethics determined by the National Association of Social Workers. Effective January 1, 1982 the person having responsibility for the direction and supervision of the delivery of such services shall be a social worker with a master's degree from a school accredited by the Council of Social Work Education, and has a minimum of four years social work experience in a health care setting including one year in a supervisory capacity.

(2) The social work staff may include baccalaureate social workers with at least one year of social work experience in a health care setting.

(3) Hospice shall have a social work department with an adequate staff to meet the medically related social and emotional needs of the patient and family.

(4) Social work services shall be provided in accordance with the plan for treatment. The social worker shall assist and work with the interdisciplinary team in identifying significant social and emotional factors related to care. The scope of socal work services shall include as a minimum: assisting in pre-admission and discharge planning; conducting medico-social assessment; counseling the patient and family on an individual and group basis; identifying, utilizing, and working to develop appropriate community resources; and maintaining adequate records relating to social work services which shall be included in the patient's medical record.

(5) There shall be continuing staff development programs and educational opportunities for social work personnel which include orientation and in-service education.

(h) **Pastoral care service:** (1) The hospice shall have adequate pastoral care services in the in-patient, out-patient and hospice-based home care program, twenty-four hour on-call availability, and a well defined written plan and policies for pastoral care services available at the request of the patient.

(2) The plan for pastoral care services shall insure the supervision of the delivery of such services by an ordained and a qualified individual with a graduate theological degree and at least five years' pastoral and clinical experience. The method for providing pastoral care to a patient or family shall be planned and developed in consultation with representatives of administration, medical staff, nursing staff, other departments and services that are involved in direct patient care, and representatives of the community.

The director of pastoral care services shall be considered a member of the health care team, with participation in all staff meetings.

(3) There shall be continuing staff development programs and educational opportunities for the pastoral care staff including orientation and in-service education.

(i) **The arts:** (1) The hospice shall provide extensive opportunities for experiences in the arts to patient/family and for staff consultation as appropriate. The arts shall be available to hospice patients both on a scheduled and intermittent basis. Designated staff providing such service shall be available on a scheduled on-call basis.

(2) These artistic experiences shall be directed and coordinated by a qualified representative of the arts with a graduate degree and clinical experience in a hospital based setting in the arts or pastoral care and a minimum of five years supervisory experience in the arts and education who, in consultation with hospice staff members and community artist representatives, will define the need, choose an appropriate art form and select the artist or means to provide this experience.

(3 The director of the arts shall be considered a full-fledged member of the health care team, with participation in all staff meetings. Written policies for the arts shall be developed and reviewed at least annually. Adequate records relating to artistic services rendered must be included in the patient's medical record.

(4) The arts staff shall complete a program of orientation to hospice and shall have appropriate in-service education programs on a quarterly basis.

(j) **Volunteer service:** (1) A director of volunteers shall be employed full time to plan, organize and direct a comprehensive volunteer services program for the in-patient, out-patient and hospice-based home care program. The director shall have a bachelor's degree in psychology, sociology, therapeutic recreation, or a related field and one year of employment in a supervisory capacity in a volunteer services program or an associate's degree and three years of supervisory experience in a volunteer services program.

(2) The director shall: (A) plan, direct and implement the recruitment of volunteers;

(B) orient and provide for a program of training which includes direct involvement, on-call service and staff support;

(C) evaluate performances and effectiveness of each volunteer annually;

(D) periodically review and revise policies and procedures;

(E) coordinate the utilization of volunteers with other directors as appropriate.

(3) There shall be continuing staff development programs and educational opportunities for the volunteer services staff to include at least the following: orientation and in-service education.

(k) **Diagnostic and palliative services:** Services, under competent medical supervision, shall be provided for necesssary diagnostic and palliative procedures to meet the needs of the hospice, in-patient, out-patient, and hospice-based home care program.

This shall include the services of a clinical laboratory and radiological services which shall meet all applicable standards of the state department of health services. In addition there may be written agreements for other services including blood bank and pathological services as determined by patient needs. All contracts shall specify twenty-four hour on-call availability.

(l) **Respiratory care services:** There shall be a written plan with clearly defined written policies and procedures governing the delivery of respiratory care services which shall include a procedure for reporting problem areas to the administrator, recommendations, solutions, and identify action taken. Services, under direct medical supervision, shall be provided as necessary to meet the needs of the hospice programs, which shall meet all applicable standards of the state department of health services. Any contract for such services shall specify twenty-four hour on-call availability for hospice in-patient, out-patient, and hospice-based home care programs.

(m) **Specialized rehabilitative services:** There shall be a written plan with clearly defined written policies and procedures governing the delivery of rehabilitative services which shall include a procedure for reporting problem areas to the administrator, recommendations, solutions, and identify action taken. Any contracts for such services shall specify twenty-four hour on-call availability for hospice in-patient, out-patient, and hospice-based home care programs.

(n) **Dietary service:** (1) There shall be an organized dietetic service, directed by a full-time food service supervisor. The food service supervisor shall be an experienced cook knowledgeable in food service administration and therapeutic diets. The service shall employ an adequate number of individuals to perform its duties and responsibilities.

(2) There shall be written policies and procedures governing all dietetic activities.

(3) The service must have at least one qualified part-time dietitian, with a baccalaureate degree and major studies in food and nutrition who is qualified for membership in and registration by the American Dietetic Association. The administration of the nutritional aspects of patient care shall be under the direction of said dietitian whose duties shall include:

(A) recording nutritional histories of in-patients;

(B) interviewing patients regarding their food habits and preferences;

(C) counseling patient and family concerning normal or modified diet and encouraging patients to participate in planning their

own modified diets and instructing patient and family in food preparation;

(D) participating in appropriate hospice rounds and medical conferences;

(E) coordinating activities with food service supervisor.

(4) Educational programs shall be offered to dietetic service employees including orientation, on-the-job training, personal hygiene, the inspection, handling, preparation, and serving of food, and the proper cleaning and safe operation of equipment.

(o) **Hospice-based home care program:** (1) The health care services of the hospice-based home care program shall be of the highest quality and shall be provided by the multidisciplinary, interactive qualified hospice team members. The program of care shall provide medical and health care services for the palliative and supportive care and treatment only for the terminally ill and their families. The hospice-based home care program encompasses the physical, social, psychological and spiritual needs of patient/family and consists of 24 hour a day, seven (7) day a week service. The services of hospice-based home care program shall include bereavement service, medical, nursing, homemaker-home health aide, pharmaceutical, dietary, pastoral care, arts, volunteers, diagnostic and palliative, social work, respiratory care, specialized rehabilitative, infection control and, as needed, in-patient and out-patient hospice services shall be available to hospice-based home care patients and their families.

(2) An organizational structure designed to effectively implement the requirements as stated in (o)(1). The medical director and director of patient care services shall be vested with the overall coordination of the hospice-based home care program. The hospice-based home care programs shall have a supervisor who shall meet the requirements of subsection (e)(2)(A), (B) or (C).

(3) The patient's primary care community physician, who is not a member of the hospice medical staff, shall be granted the privilege of requesting services provided by the hospice-based home care program in concurrence with a member of the hospice medical staff and on condition that he will continue to be the primary care provider for the patient while said patient is at home under the auspices of the home care program.

(4) There shall be twenty-four hour, seven-day-a-week on-call availability of the hospice medical director or his designee and the hospice home care nurse whether or not community service agency nurses are available. All physicians who provide medical services to patients in the hospice-based home care program, whether or not such physicians are members of the hospice medical staff, shall be evaluated as part of the regular hospice medical care evaluation program.

(5) There shall be a written policy and procedure manual implementing the objectives of the hospice-based home care program

which shall include definition and scope of services, criteria for admission and discharge and follow-up policies, and uniform standards to be adopted by the patient's primary care community physician.

(6) The hospice-based home care program shall have necessary personnel to meet the needs of patients, including: registered nurses, licensed practical nurses, and homemaker-home health aides. Personnel assigned by community service agencies to provide services to the program's patients shall meet qualification standards equivalent to those required by hospice for employees in its home care program. When volunteer services are used, volunteers shall be trained and supervised by the hospice director of volunteers or other appropriate hospice directors, and those who provide professional services shall meet the requirements of qualification and performance applied to paid staff and functions. Hospice-based home care program personnel shall be involved in educational programs relating to their activities, including orientation, regularly scheduled in-service training programs, workshops, institutes, or continuing education courses to the same extent as other hospice personnel.

(7) There shall be a program of systematic, professional and administrative review and evaluation of the program's effectiveness in relation to its stated objectives.

(8) An accurate medical record shall be maintained for every patient receiving services provided through the home care program.

(9) Arrangements for the provision of basic or major services by a participating community agency or individual provider shall be documented by means of a written agreement or contract. All hospice services available to patients in the in-patient and out-patient program shall be readily available to the home care program patients.

(p) **Infection control:** (1) Each hospice shall develop an infection prevention, surveillance and control program which shall have as its purpose the protection of patient, family and personnel from hospice or community associated infections in patients admitted to the hospice in-patient, out-patient, and home care program.

(2) The infection prevention, surveillance, and control program of each hospice shall be approved by the medical staff and adopted by the governing board. The program shall become part of the by-laws of the medical staff.

(3) A hospice infection control committee shall be established to supervise infection control and report on its activities with recommendations on a regular basis to the medical director. The membership of the committee shall include a physician who shall be chairman, a representative from nursing service, hospical administration, pharmacy, dietary service, laundry, housekeeping and the local health director.

(4) The infection control committee shall:

(A) adopt working definitions of hospice-associated infections;

(B) develop standards for surveillance of incidence of hospice related infection and conditions predisposing to infection;

(C) monitor and report infections in all patients, including home care program, and environmental conditions with infection potential;

(D) ensure evaluation of environmental infection potential, including identification whenever possible of hospice-associated infections and periodic review of the clinical use of antibiotics in patient care;

(E) develop preventive measures including aseptic techniques, isolation policy, and a personnel health program.

(5) There shall be an individual employed by the hospice who is qualified by education or experience in infection prevention, surveillance, and control to conduct these aspects of the program as directed by the infection control committee. He shall be directly responsible to, and be a member of, the infection control committee. He shall make a monthly written report to the committee at its monthly meeting.

(6) The infections control committee shall meet at least monthly and:

(A) review information obtained from day-to-day surveillance activities of the program;

(B) review and revise existing standards;

(C) report to the medical director.

(7) There shall be regular in-service education programs regarding infection prevention, surveillance and control for hospice personnel. Documentation of these programs shall be available to the state department of health services for review.

(q) **General:** (1) The hospice shall have an adequate laundry service, housekeeping and maintenance services.

(2) Proper heat, hot water, lighting and ventilation shall be maintained at all times.

(3) The hospice shall ensure the health, comfort and safety of the patients at all times.

(4) When a patient ceases to breathe and has no detectable pulse or blood pressure, the body shall be moved to the bereavement room in the same institution pending pronouncement of death by a physician who has personally viewed the body as required in section 7-62 of the Connecticut General Statutes. The facility shall make available a room which shall provide for the dignified holding of the body of the deceased person where it will not be exposed to the view of patients or visitors, but where the family and friends of the deceased may view the body.

(r) **Out-patient services:** (1) The hospice out-patient service shall meet the same standards of quality as applied to in-patient care, considering the inherent differences between in-patients and out-patients with respect to their needs and modes of treatment.

(2) The out-patient service shall be provided with services and personnel necessary to meet the needs of patient and family.

(3) There shall be a policy and procedure manual developed for the effective implementation of the objectives of the out-patient service including criteria for eligibility for out-patient care.

(4) There shall be a program of systematic professional and administrative review and evaluation of the service's effectiveness.

(5) Facilities for the out-patient service shall be conducive to the effective care of the patient.

(6) An accurate medical record shall be maintained for every patient receiving care provided by the out-patient service.

(s) **Emergencies:** Provision shall be made to maintain essential services during emergency situations.

(t) **Record availability:** It is an explicit condition for the initial issuance of or the retention or renewal of a license to any person to operate and maintain a hospice that all records, memos and reports, medical or otherwise be maintained on the premises of the facility and that said records shall be subject to inspection review and copying by the department of health services upon demand, including personnel and payroll records. Failure to grant access to the department of health services shall result in the denial of, revocation of, or a determination not to renew the license.

Chairman JACOBS. The Chair expresses the gratitude of the subcommittee for all those who enriched the record today.

The hearing is adjourned.

[Whereupon, at 12:28 p.m., the hearing was adjourned.]

[The following were submitted for the record:]

STATEMENT OF LAUREN J. WALTERS, ON BEHALF OF THE AMERICAN ART THERAPY ASSOCIATION; THE AMERICAN ASSOCIATION FOR MUSIC THERAPY; THE AMERICAN DANCE THERAPY ASSOCIATION; AND THE FEDERATION OF TRAINERS AND TRAINING PROGRAMS IN PSYCHODRAMA

This statement is submitted on behalf of The American Art Therapy Association, the American Association for Music Therapy, The American Dance Therapy Association and The Federation of Trainers and Training Programs in Psychodrama in general support of H.R. 5180, a bill to amend Title XVIII of The Social Security Act to provide for coverage of hospice care under the medicare program.

As will be outlined below, the members of these organizations provide therapeutic "creative arts" services to terminally ill persons in a variety of settings including hospices.

Our organizations are concerned that it is made clear that it is the intent of the Congress that these services be included within the context of H.R. 5180. This could best be done by adding in section 3(d)(1)(B), the words art therapy, dance/movement therapy, music therapy and psychodrama. Alternatively, these services should be considered as included in (3)(d)(1)(H), counseling.

Inclusion of these creative art therapies under the coverage of H.R. 5180 will ensure that opportunities for creative expression and for the expression of deeply held feelings in non-verbal ways are open to the terminally ill patient and his/her family.

For patients, the creative art therapies offer ways to relieve emotional strains "to provide an outlet for creativity when the time for creativity seems past."

Feelings of denial, isolation, anger, bargaining, lost opportunities, memories, depression and acceptance are well accepted stages in the dying process. Yet all to often the dying patient and his/her family are unable to express and deal with these feelings in a verbal fashion. The result is a heightened sense of frustration.

The creative arts therapies (art, music, dance and psychodrama) are perhaps, within the interdisciplinary caregiving hospice team, uniquely able to help both the patient and family express these feelings, if they choose, in a postive and creative fashion at a time when thoughts of creativity and expression seem all too absent. These mediums become ways to help the patient on the road to verbalize his feelings, anxieties, fears and hopes. Thus these therapies involve facilitating emotional growth through creative expression, an approach synthesizing psychotherapeutic techniques and creative processes permitting patients and families to settle much of the unfinished business of life.

Each therapy is used in the care of terminally ill persons and each employs different tools to deal with anxiety and fear and to bring a family closer together. Music therapy uses song writing to permit a patient to express fears, to feel more in control and as a way of defining, summing up or restructuring life experiences. Art therapy, using various art modes as a respite from the constant focus on physical needs, is a way to express feelings beyond conscious awareness, opening new opportunities for growth as well as a source of self esteem through activity utilizing strength and control.

The principals and theories of dance therapy recognize that psychological issues facing individuals are manifested physically, and that the integration of the emotional and physical life of the individual is necessary for a healthy existence. Dance therapy has been an effective tool in treating psychiatric and physically handicapping conditions. The self imposed barriers created by the terminally ill are known to alienate family members and compound the terminally ill patient's problems by breeding depression, isolation and hostility. Through creative movement exploration and non-verbal interactions, the dance therapist intercepts these barriers. Unconscious motivations become cognizable through association to one's bodily responses. The introduction of sensory stimulation devices, rhythmic movements and creative experiences recapture pleasure seeking behaviors. Spontaneity and humor are restored and a sense of self worth renewed.

Dance therapy also provides a constructive outlet for strong emotions arising from the handicapping conditions of the terminally ill. Functional and cosmetic losses have devastating effects on the body image of the terminally ill. Dance Therapy

works directly with the body and its affected parts through appropriate repetitive touch. The distorted bodily perceptions are confronted and a realistic body image replaced. Through positive corrective movement experiences the terminally ill is better able to cope with his/her illness.

The dance therapist is well prepared to treat serious psychological problems facing the terminally ill through extensive training in movement behavior and assessment, psychodynamic theory, psychopathologies, and anatomy and physiology.

Art, dance and music therapists and/or psychodramatists work, in the Hospice of Marin, California, The San Diego Hospice, The Connecticut Hospice, The DePaul Community Health Center, Chesterfield, Mo., Children's Memorial Hospital, Chicago, Union Memorial Hospital Hospice program, Baltimore, Maryland, Sloan-Kettering Memorial Hospital in New York, the Hospice in Montreal, Canada and numerous oncology programs around the country.

Attached to this testimony, for inclusion in the hearing record, are several articles and other material describing the use of creative art therapies in the care of the terminally ill in hospices and other settings.

[Attachments have been retained in the subcommittee files.]

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STATEMENT OF THE AMERICAN ASSOCIATION OF HOMES FOR THE AGING

The American Association of Homes for the Aging (AAHA) wishes to take this opportunity to express support for the passage of H.R. 5180, a proposal to provide coverage of hospice care under the Medicare program.

AAHA represents nonprofit homes for the aging, housing and health-related facilities. Its nearly 2,000 member homes are located throughout the United States and are sponsored by community-based religious, fraternal, labor, civic and county organizations dedicated to quality care for the elderly residents of the home and the community at large. Many of these homes participate in Medicare and/or Medicaid as skilled nursing facilities. Others provide intermediate care, personal care and housing; many are multi-level campuses offering an array of services to meet various stages of need.

A great many AAHA homes offer one or more outreach services as well. Whether through outreach or services to the home's own community of residents, AAHA homes strive to offer the kind of comprehensive, interdisciplinary care envisioned by H.R. 5180. Most homes, in fact, do provide what could accurately be termed "hospice" care, either through programs identified as such, through home visitation, or through skilled care and support services to residents who may be terminally ill. For these reasons, nonprofit homes for the aging are vitally interested in the legislation in question.

Since the first hospice program in the United States opened its doors less than ten years ago, hospice has grown to be recognized as an increasingly popular alternative to traditional treatment for the dying. Hospice stresses intensive care—and caring—at a time when curative treatment is no longer appropriate, according to the best judgment of the terminally ill person and his or her physician. Hospices in this country tend to emphasize care in the patient's home, in the comfort of familiar surroundings and among people and things most meaningful. On those occasions when it is not possible to arrange sufficient or suitable home care, or when other facilities are needed for short-term symptom control or respite care, then inpatient care can be arranged. Whatever setting the person is in, hospice care is the antithesis of acute, hospital-based care. Where hospital care attempts to get at the cause of an illness, hospice care accepts the cause and seeks to manage physical and emotional pain so that one can accept impending death.

Unfortunately, to date, private health insurance policies and the Medicare and Medicaid programs distinguish between acute care and hospice care, providing payment for the former but not the latter. This is so because of services found in a hospice program often do not fall into the neat categories and definitions of what is considered reimbursable.

Consider the example of an elderly woman, eligible for Medicare, who has terminal cancer and whose physician has determined that she has less than six months to live. Family members would like to care for her, but they need the part-time services of a nurse and someone to perform household chores when no one can assist at home. The federal government's Medicare package will pick up the cost of the nurse's hourly visit, providing the services conform to a number of conditions. One of these is that the nurse perform no "custodial" chores, such as delivering a meal or preparing one, assisting in bathing or dressing the woman, or tending to other personal needs. Also at home, Medicare will not pay for drugs, including any pain

killers she might require. But if the woman entered a hospital, Medicare would cover both these services and drugs.

Current private health insurance policies have similar payment rules. As for the Medicaid program for the poor, the federal government establishes by law the basic benefit package (similar to Medicare's), and few states are willing to tack on additional services at added cost to both governments.

A theoretical hospice package ideally includes not only home care and coverage of drugs, but also special pain consultations from a nurse or physician, a social worker to assist the patient and family through the time of illness and bereavement, a clergyman for spiritual help, and someone who can maintain daily contact with the patient. To provide these services today involves piecing together, in a complicated mossaic, specific government or private health insurance benefits with services from volunteers, funds from charitable organizations, and anything that can be gotten from the patient and family. H.R. 5180 would provide comprehensive coverage of hospice care under the umbrella of the Medicare program and, in doing so, help resolve the red tape now involved in pulling together a program of care funded by a variety of resources.

Although hospice care is not cheap, it pales in comparison to the cost of a hospital stay. Various studies suggest that hospice services are far less expensive than traditional forms of terminal care. Yet even the choice of hospice setting can have a significant effect on the potential for cost savings. A recent National Cancer Institute study found that nursing home-based hospices seem to provide more cost-effective care than hospices affiliated either with health maintenance organizations (HMOs) or hospitals.

The NCI study looked at the costs of home care, inpatient care and per patient costs for facilities sponsored by a nursing home, a federally qualified HMO and a hospital. The findings indicated the nursing home hospice cost less for two of the three areas surveyed. Comparisons were made by averaging the three facilities' costs, then noting the dollar and percentage differences between that average and the cost of each facility. The cost per inpatient day at the nursing home was 38.5 percent below the average, the study showed. (Inpatient costs ranged from $143 for the nursing home, $250 for the hospital and $306 for the HMO.) The nursing home did rank above its counterparts in cost per home visit. (The nursing home-based hospice visit cost $91, compared to $60 for the hospital and $90 for the HMO.) But at the same time, the overall nursing home cost per patient was lowest, totaling 12.5 percent less than the average. (Per patient costs ranged from $3,204 for the nursing home to $3,223 for the hospital and $4,554 for the HMO.)

The study, the first analysis of cost effectiveness and differences between the three major forms of hospice care, suggests that in some cases, free-standing comprehensive hospices may not be cost-effective because of the large staff requirements and patient load limitations.

The experience of existing hospice programs, as examined by the National Cancer Institute, the Blue Cross studies and an independent analysis by the Warner-Lambert Foundation, suggests that substantial savings would likely result from encouraging the availability of hospice care. All of the studies that have compared the costs of hospice care and traditional care of the terminally ill have reported savings associated with the substitution of palliative care for the more expensive curative care. One study estimated that reimbursement of comprehensive hospice care would save Medicare between $13 and $50 million in the first year, rising to between $30 and $130 million by year five. In this time of competing demands and budget custs, H.R. 5180 offers Congress the opportunity to provide much-needed help at very little cost.

In light of these findings, AAHA is pleased to note that H.R. 5180 specifically allows for a hospice division of a nursing home to participate as a Medicare provider of these services. It is our hope that in the implementation of this legislation, once adopted by Congress, the Department of Health and Human Services will quickly undertake, with the widest possible public input, to define a fair and equitable method of reimbursement for hospice programs according to standards that are most conducive to the provision of quality care and services.

AMERICAN COLLEGE OF RADIOLOGY,
*Chicago, Ill., March 26, 1982.*

Hon. ANDY JACOBS, Jr.,
*Chairman, Subcommittee on Health, Committee on Ways and Means, Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: The following comments on HR 5180 are offered on behalf of the 16,000 members of the American College of Radiology and the 1500 members of the American Society of Therapeutic Radiologists. Members of the ACR are physician specialists who use ionizing radiation to diagnose and treat disease. Members of the ASTR are those radiologists who have specialized in the use of high energy radiation to treat cancer patients.

We applaud the intent and purpose of HR 5180. In represents recognition of hospices as an enlightened and effective mechanism for providing terminal care.

We want to call to the subcommittee's attention several points concerning the palliative services of radiotherapists to terminal patients which, we hope, can be reflected in the language of the bill.

Therapeutic radiologists have intensive experience in dealing with dying patients, principally those whose cause of death is some form of cancer. Often, they share in the medical decision to discontinue vigorous curative efforts.

Prior to a patient's admission to a hospice program, the therapeutic radiologist and his oncologic colleagues would have referred that patient back to his primary physician. However, even when the outcome is accepted, there remain some palliative efforts which can affect beneficially the waning months of life. These relate to the control of pain and the retention of body function and some degree of self-sufficiency.

For some cancer patients, the spread of disease beyond its primary site brings pain as the tumor impinges upon nerves. For some, radiation treatments may be the medical management of choice to shrink the edges of the tumor and relieve pain. Similarly, shrinkage of incurable tumors by radiation may allow a patient to retain the ability to eat normal food, to void, to walk and otherwise to care for himself. In money terms, coverage of such palliative radiation could be a very effective tradeoff against a probable need for more intensive care.

Modern radiotherapy is administered in medical centers equipped with sophisticated radiation generators, massive shielding and a trained team of doctors and scientists. A hospice patient requiring palliative radiation woud need to be transported to a therapy center for each treatment. Some centers are located in acute care hospitals. Others are free-standing facilities. An adequate center could be found in most American cities. It seldom would be necessary to transport a patient over a long distance.

As we turn to the language of the bill, we are grateful that the sponsors of HR 5180 recognize the need for palliation in language in section 5, which amends section 1862 (a) of the existing Social Security Act. Similarly, the language in section 4, which amends section 1861 covers in (dd)(1)(F) physicians' services and (G) "short-term inpatient care (including both respite care and procedures necessary for pain control and acute and chronic symptoms management) in an inpatient facility. . ." is helpful in guaranteeing our objective.

We urge that a further phrase be inserted to stipulate that such care might also be provided on an outpatient basis in free-standing cancer treatment centers. Such coverage would allow the option of avoiding a hospital admission with accompanying costs to the hospice patient whose care does not require such admission. It would also avoid unintended discrimination between radiation therapy facilities on the basis of their location and affiliation.

Further, we are concerned that language in section 2, amending section 1812, by adding (d)(2)(A)(ii) appears to preclude the services of a physician (such as a radiotherapist) who does not meet the reasonable description of the patient's attending physician during the time the patient has opted for hospice care. The insertion of a phrase after "attending physician" which could state "or other physicians providing palliative services" would accomplish this end.

As a final comment, HR 5180 does not address the question of whether or not ambulance service benefits otherwise available to Medicare beneficiaries are foreclosed by the hospice care option. Some terminal cancer patients can be transported by automobile. Some, unfortunately, would require an ambulance to take them to and from a hospital or other cancer treatment facility.

Thank you for the opportunity to offer these suggestions. If we can provide additional information, please contact us through the ACR Washington Office and our legislative counsel.

Sincerely,

JOHN H. HARRIS, Jr., M.D.,
*Chairman, ACR Board of Chancellors.*
HERMAN SUIT, M.D.,
*President, ASTR.*

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STATEMENT OF THE AMERICAN DIETETIC ASSOCIATION

The American Dietetic Association (ADA), an organization representing 46,000 nutrition professionals, supports legislative initiatives to provide Medicare reimbursement for hospice care both in a home and in an inpatient setting. As health care providers, we concur with the hospice philosophy of providing terminally ill patients with the opportunity to lead a full life, with dignity and enhanced selfworth, during their remaining months and days. We believe that reimbursement for hospice care, as an alternative to curative care for those patients desiring such services, makes sense—from a humanitarian and public policy standpoint and, as numerous studies have demonstrated, from a financial standpoint.

The ADA is particularly interested in H.R. 5180, especially the language which addresses provision of nutrition care to the dying patient. While we are pleased to see reference to the provision for "dietary counseling" in H.R. 5108, we recommend that the language "dietary counseling" be replaced with "nutrition services provided by or under the supervision of a registered dietitian" to ensure comprehensive nutrition care. The Association strongly believes that nutrition services should be integrated into all health care delivery systems; and that these services should include assessment of nutritional status, dietary counseling, nutrition education, and provision of and/or referral to food assistance programs or other necessary services.

Nutrition is a vital concern to terminally ill patients and their families. these atients are faced with a variety of complex nutritional problems such as anorexia, dehydration, rapid weight loss, tube feedings, diabetes; pancreatic, renal and liver involvement; malnutrition and adverse reactions to medications and drug therapies. An example of the level of need for nutrition services is evidenced by a tally of data from the Hospice of Northern Virginia (Arlington, Virginia) during the week of March 8, 1982. During this typical week, 60 percent of the hospice patients receiving home care required dietary modification, while 67 percent of inpatients received therapeutic diets. Other surveys also indicate that 60 to 70 percent of hospice patients require some type of dietary modification to enable them to live out their remaining days in as much comfort as possible.

Recognizing and treating these dietary problems is accomplished most efficiently and effectively by the Registered Dietitian (R.D.). The Registered Dietitian has a baccalaureate degree from an accredited college or university, has completed a dietetic intership or comparable experience, has passed a writen examination, and maintains continuing education requirements. Thus, the public can be assured that the R.D. is competent to provide a comprehensive range of nutrition services.

When visiting the patient and completing a nutritional assessment, the Registered Dietitian will note general appearance, weight change, dentition, bowel habits, fluid retention and pain involvement. Allergies must be noted, as well as the ability to communicate, chew and swallow. Observations will be made about the patient's food preferences and intolerances, as well as the presence of nausea or vomiting, mouth sores or a dry mouth. If the patient is experiencing anorexia, a determination will be made as to its source, e.g., drug interference, depression, or disease progression.

After assessing nutritional status, the dietitian is in an excellent position to counsel ahd patient and/or family about the plan for nutrition care, to provide educational materials which may be helpful (e.g., foods well tolerated by the cancer patient), and to make any referrals that may be necessary.

We recognize that some basic nutrition care may be delegated effectively to other professional staff; however, it is the Registered Dietitian who is uniquely qualified through education and training to supervise the provision of basic nutrition care and render services in more complex situations. To utilize a professional whose major emphasis in training is other than nutrition, significantly increases the potential for errors in interpretation of data, for inefficiency, and possibly for more visits being required—all of which raise expenditures. Furthermore, direct provision of nutrition services by a Registered Dietitian can free a nurse or other staff

member to provide services to a patient while the dietitian is providing nutrition care.

In our current economic situation, it is of prime importance that any new health initiatives undergo cost-benefit analyses. Providing reimbursement for hospice care will not bring additional people into the Medicare system. These individuals are already receiving care in acute or long-term care facilities. Studies by the National Cancer Institute, Blue Cross and Warner-Lambert suggest that hospice services, when substituted for traditional forms of care for the terminally ill, are less expensive.

The independent Warner-Lambert analysis projects a net savings to the Medicare program of at least $15 million during the first twelve months after enactment, and projects a net savings to Medicare in the fifth year after enactment rising to as much as $130 million.

In sum, the ADA supports initiatives to provide hospice care to Medicare recipients as a humanitarian and cost-effective measure. We believe that hospice patients should receive comprehensive nutrition services provided by a Registered Dietitian, the only health care provider professionally trained to provide nutritional assessment, counseling, education and referral. Consequently, we recommend that reference to "dietary counseling" on page 11, Section 4(dd)(1)(H) be struck and that (I) be added to read, "nutrition services provided by or under the supervision of a registered dietitian," as indicated in the enclosed revision. Such a revision will ensure that dying patients will receive comprehensive nutrition services which will contribute to their comfort and quality of life.

We welcome this opportunity to provide our testimony for the record and would be pleased to assist the Committee upon request.

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STATEMENT OF MORRIS B. LEVY, EXECUTIVE DIRECTOR, AMERICAN FEDERATION OF HOME HEALTH AGENCIES, INC.

My name is Morris Levy. I am the Executive Director of the American Federation of Home Health Agencies (AFHHA). I am very pleased to be able to present testimony to the House Ways and Means Committee on H.R. 5180, a bill to amend title XVIII of the Social Security Act to provide for coverage of hospice care under Medicare. While AFHHA supports the concept of Hospice care in the home, H.R. 5180 does not provide the soundest and least costly method of providing this care.

The AFHHA is a national trade association representing nonprofit and proprietary small business home health agencies across the United States. It was formed in September 1980 to present a carefully reasoned picture of the small business sector of the home health industry to the Congress and the Health Care Financing Administration. The AFHHA believes that constructive input on behalf of the small business sector of the industry has been noticeably lacking in the past. The AFHHA represents a greater percentage of the small business sector than any other national organization representing the home health industry.

While I have been the Executive Director of AFHHA only since January 1982, I personally have had long experience observing and interacting with the home health industry in administering the Medicare and Medicaid programs for the Federal government. I was a member of a special Medicare Task Force established by the Social Security Administration in 1964 to plan the administration of the Medicare program, and beginning with the enactment of Title XVIII of the Social Security Act in 1965, have held a number of executive level positions in the Health Care Financing Administration and its predecessor agency, the Bureau of Health Insurance. At the time I left HCFA to assume my present responsibilities, I was the Acting Director for Program Policy.

H.R. 5180 would expand the scope of Medicare's coverage of health care services to include hospice care. Hospice care involves the provision of skilled and compassionate care to the dying and their families. Hospice care is not oriented toward the cure of patients but rather to their care, since terminal patients are not going to be cured.

Hospice care is concerned with treating the patient's symptoms--physical, emotional, spiritual and mental. A major goal of hospice care is to palliate the symptoms to enable patients to spend what remains of their lives in the maximum comfort possible. The principal goals of hospice care are to attempt to provide relief from the most pressing symptoms, provide a secure caring environment, continuous professional care, and assurance to the patient and his or her family that the patient will receive care as long as required.

Mr. Chairman, the AFHHA wishes to emphasize that while hospice care, per se, is not now covered under Medicare, many of the individual components of hospice care are covered. Many of the services rendered to terminally ill patients are covered by Medicare on an inpatient, outpatient and home care basis. The almost 3000 Medicare certified home health agencies provide services each day to the terminally ill in their places of residence who qualify for Medicare home health coverage.

However, present Medicare coverage requirements limit the circumstances under which services can be provided to terminally ill patients at home as well as the scope of such services. For home health services to be covered under Medicare, the patient must be homebound and have the attending physician order the required skilled nursing, physical therapy or speech therapy. Patients who are homebound and who require part-time or intermittent skilled nursing, or one of the therapeutic services they may be covered for skilled nursing services and other therapeutic services required, as well as medical social services, the part-time or intermittent services of home health aides, medical supplies (other than drugs and biologicals) and the use of medical appliances.

Terminally ill patients often require skilled nursing services on a part-time basis as well as physical therapy, speech therapy, and home health aide services when the physician orders these services for their patients who are homebound. When required by patients who must remain at home, they are furnished by Medicare approved home health agencies along with other services covered by the Medicare home health benefit.

Occasionally terminal patients are not homebound according to the Medicare definition, because even though terminally ill they may be able to leave their homes without the aid of special supportive devices or special transportation. Terminal patients may not require the skilled services which include, observation and evaluation, training and teaching, or the direct services that can only be safely and effectively performed by a skilled professional. Frequently, these patients may for periods of time, need personal care, i.e., assistance in walking, getting into and out of bed, bathing, toileting, dressing, feeding, supervision of medications and/or social and psychological support and these services would be excluded from Medicare coverage since skilled or therapeutic services are not needed.

Other terminal patients living at home, depending on their circumstances, may require extended nursing care for several hours each day or around the clock. Medicare, under presently written guidelines, does not cover such services when furnished in the home. Skilled nursing must be furnished on a part-time, intermittent basis to be covered by Medicare. Medicare defines part-time and intermittent to mean services generally for a few hours a day several times a week for up to two to three weeks. Medicare's coverage guidelines specify that an individual expected to need more or less full-time skilled nursing care over an extended period of time would require institutionalization and would not usually qualify for Medicare home health benefits. Under no circumstances would Medicare cover bereavement follow-up visits or social services visits to the deceased patient's family.

As can be seen, there are gaps in the services Medicare now covers for the terminally ill who choose to reside at home. And, certain custodial and psychological type services required by the terminally ill, even in an institutional setting of a hospital or skilled nursing facility are not covered by Medicare.

HR. 5180 would close these gaps in services that could be provided to terminal patients in their places of residence. We believe that, if granted a choice, most individuals would prefer to die at home with their family and those whom they love at hand. Unfortunately, our society today institutionalizes death. It sanitizes it from family and loved ones. In our society, the dying meet death usually alone, in the stark surroundings of a hospital or nursing home room.

In a recent book, The Hospice Movement: A Better Way of Caring for the Dying, by Sandal Stoddard (Briarcliff Manor, N.Y., Stern and Day 1978), Stoddard cites William Lamers who makes the point:

"The dying have the right to a great many things that hospitals and nursing homes simply cannot provide. They need life around them, spiritual and emotional comfort and support of every sort. They need unsanitary things, like a favorite dog lying at the foot of the bed. They need their own clothes, their own pictures, music, food, surroundings that are familiar to them, people they know and love, people they can trust to care about them. Hospices can provide this in their inpatient units, and yet, for many individuals and their families, it is much better for it to happen at home."

Mr. Chairman, we believe wherever possible hospice care should be provided at home, and we would point out that the nearly 3000 Medicare approved home health agencies are fully qualified to provide this care. Many of these agencies have been

operating since Medicare began in 1965, and some even before the advent of Medicare. Each day these agencies provide much of the services described in H.R. 5180 as hospice care. And, if Medicare coverage is expanded to include the services described in HR 5180, but not presently covered by Medicare, those agencies would secure the needed resources and are qualified to provide those services. Home health agencies currently participating in Medicare must meet extensive health and safety requirements to participate. They must undergo a rigorous survey and review process by the State certifying agencies. The State survey results are carefully reviewed by the HCFA.

Despite the existence of these many qualified agencies, HR 5180 would establish a new class of providers, designated as a hospice program. The home health agencies, who have been providing home care services to the terminally ill, would have to undergo a new survey by the State certifying agencies. They would have to meet new and additional requirements established by the Secretary. If they now operate in a state with a hospice licensing requirement, they would have to obtain State approval to provide the services they have been providing for these many years as a home health agency. Requiring agencies that already have demonstrated they meet Medicare's home health and safety requirement go through another survey does not add to the quality of care they provide.

Mr. Chairman, the AFGHA sees no need to establish a whole new class of providers, with separate certification requirements, to provide services at home for terminal patients which currently certified home health agencies already provide. Separate requirements and separate surveys cost money. This money could best be spent in providing care and not in duplicating requirements that already exist. It is also, in our judgment, unfair to require home health agencies who meet the stringent state licensure provisions for home health care to have to be relicensed to provide basically the same kind of care they have been providing. We are fearful that licensure of hospices will be handled by a different State agency than that which licenses home health agencies.

If hospice care is to be provided through HR 5180, then a provision should be included to require utilization of existing Medicare certified home health agencies in delivering hospice care. Home health agencies, of course, would need to furnish the necessary assurances as to the number of days of inpatient care and demonstrate compliance with other requirements in HR 5180. For instance, they would have to meet the interdisciplinary personnel requirements specified in the bill. Home health agencies would also make those necessary arrangements as specified in HR 5180 to have care provided, when needed, with an inpatient facility.

If the provisions of HR 5180 providing for a new class of providers were to be enacted it very likely would drive up the costs of home health care under Medicare. Under HR 5180, home health agencies, not certified as hospice programs, would lose a significant number of terminal patients they had previously been treating, to hospice programs. Treating fewer patients, their unit costs would undubtedly rise. The increase in unit costs would, in many instances, exceed the home health cost caps creating severe financial hardships. It is not too difficult to envision a scenario where a number of home health agencies will be forced to cease operations. This would be indeed calamitous for Medicare since home health agencies are lower cost alternatives to institutionalization. Indeed. at a time when the government should be encouraging the use of home health care, because it is less costly than institutional care and enables the patient to be treated in the familiar surroundings of his or her home, this bill would lead to cutbacks in home health care. For those home health agencies able to continue their operations, the higher costs experienced, would under Medicare regulations be included in determining subsequent cost caps at a higher level. Thus in later years Medicare would be paying home health agencies at these high levels as well as the costs of hospice care.

While HR 5180 attempts to deal with many of the Medicare coverage gaps in treating the terminally ill, this Committee should understand that its features are likely to be quite costly. HR 5180 provides up to a full year's benefit for terminal patients. Unlike the present Medicare home health benefit, which provides part-time services about three times weekly, hospice care would involve daily nursing services for several hours or more, and much more frequent and extensive homemaker and home health aide services than provided under the Medicare home health benefit. Although the bill will attempt to set cost limits, those limits will reflect the cost experience of providing hospice care more frequently and for more extended periods of time.

As you know, Mr. Chairman, the HCRA currently has a hospice demonstration program underway that, among other things, will obtain cost data on furnishing hospice care. We understand that HCFA, at present, only has preliminary cost data

available from its demonstration program. These data include start up costs for hospice providers and HCFA advises us that the preliminary nature of the data makes it impracticable to draw even preliminary conclusions of what hospice care will cost.

Moreover, we are concern about the methodology used to date to establish the putative savings of hospice care. The information we have seen only compares costs between hospice care and inpatient care. But, no information has been provided comparing the costs of hospice care and home health agency terminal care. For instance, Senator Chiles, in commenting on S. 1958 in the *Congressional Record* of December 15, 1981, points out that Medicare hospital costs for 6 months of terminal care comes to about $7,000 per case compared to $4,500 for hospice care furnished by a free-standing hospice. Senator Chiles cost analysis does not proceed to the next, less costly, level of health care for the terminally ill—the home health agency. AFHHA's preliminary data indicates that home health agency terminal care costs are well under $2,000 per case. For example, one certified home health agency's licensed full service hospice program in South Florida shows a year end average cost, as of December 1981, to be $938.86 per terminal case for 122 patients.

We have some indications from England's experience that hospice care is not cheap. For instance, Holden in an article in *Science* (July 30, 1976), "Hospices: For the Dying; Relief from Pain and Fear," reports that in England, the per-patient cost is about 80% of that in a general hospital, and about 85% of the budget goes to staff salaries. Hospices provide extensive and comprehensive nursing care. Stoddar ("The Hospice Movement: A Better Way of Caring for the Dying," Briarcliff Manor, New York; Stein and Day 1978) indicates that hospices require a higher nurse-patient ratio than in hospitals or nursing homes. Kenneth P. Cohen reports ("Hospice; Prescription for Terminal Care," Aspen Systems Corp., Germantown, MD 1979) that one study indicated hospice inpatients require approximately nine hours of nursing care per patient day, not including volunteer assistance. Cohen also indicated that the cost of home care has been estimated to be about 50% less than that of inpatient care with outpatient care falling somewhat in between.

The AFHHA would like to see this Committee obtain more information about the estimated cost of the provisions in HR 5180. In particular, cost information should be obtained from the HCFA demonstration project. We believe cost data are essential before making a judgment about expanding coverage in today's critical budget climate.

There are several provisions of the bill that the AFHHA believes require further study or should be deleted. These include the provision which acts to preclude a patient who is receiving hospice care from having Medicare reimbursement made to other providers, the revocation provisions which can result in a waiver of the patient's rights to have payments for hospice care for the balance of the 180 day coverage period, the reimbursement methodology, and the provision precluding discontinuance of care due to inability to pay.

H.R. 5180 would also provide that while hospice care is being furnished through a hospice program, Medicare payments would not be made to other providers (except the patient's attending physician) for services which are related to treatment of the individual's terminal illness which are equivalent to or duplicative of hospice services. We believe this would be extraordinarily difficult to administer. For instance, would a patient who is at home dying without a written "no-code order," who must be hospitalized because of a series of cardiac seizures face the loss of coverage of his or her hospital stay because the services are deemed duplicative? Would a terminally ill cancer patient, who is hospitalized for a myocardiac infraction, not be covered because of a determination he or she is receiving equivalent services to hospice care?

H.R. 5180 also contains a provision that an individual could revoke the election of hospice care during a 180 day period and change from one hospice to another during the period. But, if the patient revoked the election, the remaining portion of the 180 day period wold be forfeited. We believe this constitutes an unusually harsh provision. It effectively locks in the dying patient to a Hospice provider. If the patient or his family, for whatever reason, is dissatisfied with the care provided, the individual would presumably forfeit covered care for the balance of that 180 day period.

H.R. 5180 would establish a completely new system of cost caps for patients receiving hospice care. While the methodology for determining these caps is different from the methodology now followed under Medicare for determining cost limits, it still is based on a retrospective reimbursement system. The AFHHA has testified before this Committee on previous occasions that Medicare's retrospective reimbursement system encourages cost escalation. This is because providers understand that under a retrospective system payment is made to providers for costs incurred. Thus, there is no incentive for lowering costs. H.R. 5180 also provides that the

Comptroller General will study the reimbursement system established by the bill and recommend whether a prospective methodology is feasible and advisable. We believe that further study of prospective reimbursement only tends to delay institution of this much needed reimbursement system. The AFHHA urges that HCFA move now to being developing a prospective system for HHA's and other providers, and the AFHHA has offered to work with HCFA in developing this system.

Mr. Chairman, to summarize our comments, AFHHA supports the concept of hospice care, but feels the expansion of Medicare coverage as stated in H.R. 5180 needs to be evaluated carefully. Before this Committee makes a decision it should explore the cost implications of this step. If a decision is made to expand coverage along the lines of this Bill, we do not agree that home hospice care requires a new class of providers. Home Health agencies now and over the years have provided services to the terminally ill. There is absolutely no reason why they are not qualified to continue to provide these services and the additional services contemplated by H.R. 5180 without having to qualify as a new class of provider. Finally, there are a number of provisions in H.R. 5180 that we believe require further study or clarification. The AFHHA would like to offer it services in the further consideration of this proposed legislation, and would be pleased to work with the Committee's staff on this effort.

We thank you for the opportunity of offering our comments on this significant legislation.

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STATEMENT OF THE AMERICAN HEALTH CARE ASSOCIATION

The American Health Care Association, the nation's largest organization of long term care facilities, is pleased to present our recommendations on improved coverage for terminally ill individuals under the Medicare program. Our nearly 8,000 facility members serve 750,000 individuals in need of institutional long term care and increasingly provide a broad range of community and home-based long term care services.

Long term care facilities are primary providers of terminal care. The National Center for Health Statistics reports that nursing homes provided care for 289,800 patients who died in the facility during 1976. Thousands more patients needed to be transfered to hospitals or other health facilities where they later died. The three leading primary diagoses at admission for those who died in a nursing home were arteriosclerosis (60,700 patients), cancer (44,700), and stroke (41,500). The terminal care was provided to short term and long term residents—44 percent had a stay of less than 3 months and 37 percent had been in the facility for over 1 year.

Nursing homes are relied upon to provide terminal care mostly to people who have no family resources available or who have greater needs than their families are able to handle. This role in terminal care is indicated by some basic figures about nursing home residents: the median age is 81; 88 percent have no spouse; and 71 percent were admitted from a health facility, usually hospital, or had lived with their children or other relatives.

The nursing homes which provide terminal care strive to have around-the-clock visiting hours to family and friends of the dying; direct their care toward comfort measures rather than extraordinary curative measures when appropriate; conduct staff training on the special needs of dying patients and their families; provide respite care for dying patients in order to periodically relieve their families; and often provide outreach home health services to dying patients who are being cared for in their homes. Care of the terminally ill is long term care and long term care facilities are leaders in caring for these people. We recognize the importance of this responsibility and are proud of our performance.

AHCA supports improvements in the Medicare program to better meet the health needs of terminally ill beneficiaries and encourage the more economical and efficient provision of terminal care. We suggest the following principles be used to consider the expansion of Medicare benefits and provide our comments on the application of each to H.R. 5180.

1. When Medicare pays less than 40 percent of the elderly's total health expenses and program cutbacks were made last year for budgetary reasons and deeper cuts this year, expansion of benefits should be made cautiously and only in those areas of proven cost-effectiveness.

It is apparently necessary to clarify what the major issue if for this hearing and as presented by H.R. 5180. It is not whether Medicare should cover care provided to terminally ill beneficiaries—it already does. It is not whether Medicare should cover

care provided by hospices—it already does. The issue is whether Medicare coverage for hospices should be expanded to special terminal care benefits.

The hospice concept is a very recent and still evolving addition to the American health care system. Hospices have rapidly flourished in number and exhibit a wide variation in such characteristics as costs and financing, services and delivery arrangements, setting, and organizational structure.

To examine the potential value of the hospice concept for Medicare and Medicaid recipients, the Health Care Financing Administration undertook one of its largest service demonstrations. The 2 year, 26 hospice project will soon begin to yield factual information useful to evaluate the utilization and cost impact of hospices, suggest what specific hospice services should be covered, develop innovative reimbursement methods, and determine the appropriate regulation of hospices. Early indications from this demonstration are reportedly mixed and inconclusive.

Other Federal studies and private insurer experience provide some support for greater use of hospice care in narrow applications and controlled circumstances. We suggest the information to date supports an incremental approach to improving terminal care coverage, but does not provide sufficient basis for enacting such a generous commitment to one form of terminal care as embodied in H.R. 5180.

We know first hand the problem created by the rapid growth of a provider industry in response to greatly expanded Federal coverage. Similar problems have occurred with kidney dialysis centers, prepaid health programs, and Medicaid clinics. Hospice proposals should be considered from the "worst case" perspective, not merely a projection of the best experiences. We urge the Congress to proceed with full analysis and dispassion to aviod unintened, unanticipated, and unfortunate consequences. In particular, close and careful attention needs to be given to cost containment, quality assurance, utilization review, and provider regulatory and reimbursement procedures. This hearing is an important first step, but the environment is still too emotion laden to accommodate an open dialogue about care of the dying.

AHCA recommends that Medicare and Medicaid coverage be continued only for the hospices in the HCFA demonstration until Congress has had an opportunity to consider the final evaluation report.

2. The focus should be on what services Medicare should cover and assuring that patients with similar needs be covered for similar benefits.

A major fault with H.R. 5180 is that it is oriented toward expanding the role of hospice as the terminal care provider, rather than expanding benefits to better meet the needs of the terminally ill. The bill proposes expansive coverage of terminal care services and items but only when provided by or through a hospice. The bill does not provide any benefit improvement to terminally ill Medicare patients outside of a hospice nor other Medicare patients with comparable care needs. the intolerable situation could be set-up under H.R. 5180 in which two patients were dying side-by-side in a skilled nursing facility, but one gets higher benefits because of being covered through a hospice.

The hospice approach can be one way, but not the only way, to care for the dying. It is not and will probably never become even the most common way. The variety of patient health needs and personal circumstances requires a diversity of service arrangements.

We must express specific concerns about the priority and advisability of some of the new benefits which would be provided under H.R. 5180. Reimbursement for services to family members of Medicare beneficiaries, notably three bereavement counseling sessions, is inappropriate. Medicare is already facing severe financial problems and we doubt if extending services to people outside the program can be cost-effective. Any extra funding available to the Medicare program should be used to fill the elderly's benefit gaps. H.R. 5180 would also cover pastoral, or religious, counseling. Some patient's desire for this service is understandable and our facilities make it available. However, it is questionable that pastoral counseling should be a reimbursable expense under a government program. The most far reaching, but little noticed, benefit expansion would be made by Section 5 of H.R. 5180. From the beginning, Medicare has excluded from coverage items and services which are not reasonable and medically necessary, constitute personal comfort items, or are for custodial care, unless expressly provided for by statute. H.R. 5180 provides an open-ended exception for such items and services if they are "for the palliation and management of terminal illness."

It is not clear what is the intention of this broad exception. For example, would there be an exception to the Medicare policy of considering as custodial care the services of a Medicaid certified intermediate care facility? Could an unlicensed boarding hotel be reimbursed for custodial care?

What about other items and services that are not now reimbursable? Radios, televisions, telephones, air conditioners, and special beauty and barber services (e.g. manicures and hair styling) are the specific personal comfort items listed as not reimbursable for SNF patients. For which of these is reimbursement sought?

If Congress begins to make exceptions for unspecified personal comfort items, custodial care, and non-medical services, then these items should be available according to patient need, not predicated by disease or provider or life expectancy. There are many categories of patients who would have at least as important need for any such new coverage as the terminally ill.

3. Any provider should be permitted to deliver Medicare covered services as long as the provider complies with performance standards and other provider requirements.

H.R. 5180 basically creates a new category of Medicare providers to deliver expanded terminal care benefits. AHCA finds no reasons for creating further fragmentation of Medicare service delivery by creating a new provider designation, unless for puposes of different provider regulation which H.R. 5180 does not propose to do. Any terminally ill Medicare beneficiary should be eligible for coverage at these expanded benefits regardless of whether in a hospice or other setting. It should be restated that hospices are already providers of Medicare covered services and H.R. 5180 basically proposes to expand covered benefits.

If Congress does create a new provider category the definition used in H.R. 5180 should be revised. Part of the provider definition is that no more than 20 percent of its patient days be used for inpatient care. This is an inappropriate provider distinction as well as financially unnecessary. Since H.R. 5180 includes a cap on provider reimbursement, providers should have the flexibility to use inpatient days as they find necessary and without arbitrary restriction. Also, we find no justification for a physician and other specified personnel being "employed" rather than available through other standard arrangements such as contracts or that the use of volunteers is a relevant provider distinction.

The provision of present Medicare terminal care services could be improved if the present discrimination against skilled nursing facilities as terminal care providers were removed. SNFs are often a more appropriate setting for terminal care and certainly much less costly alternative to hospitals, in which most of the Medicare covered terminal care is currently provided. But Medicare does not recognize terminal illness as a sufficient patient condition for SNF coverage.

AHCA recommends that Medicare allow SNF coverage for care of the terminal ill. Substantial progress could be made by this cost-effective utilization of SNFs, even with the normal 100 day limit on stays and patient co-insurance for SNF coverage. Such an improvement would be more productive if accompanied by the elimination of the minimum 3-day prior hospitalization requirement for SNF coverage. Indications of the value for terminally ill Medicare beneficiaries of SNF coverage without the required prior hospitalization are presented in a recent HCFA study in Oregon and Massachusetts. Of the Medicare beneficiaries admitted directly to an SNF, the admission diagnosis was either cancer or cerebrovascular accident for 33 percent of Oregon and 23 percent in Massachusetts.

In summary, AHCA advises that altering the Medicare program to create a new type of coverage be approached cautiously. Serious study must be given to Medicare's current financial problems and the way this bill could aggravate those problems. We have serious reservations about extending Medicare coverage to such non-medical services as counselling. Finally, we suggest that care to the terminally ill could be enhanced more cost-effectively through minor changes in Medicare law that encourage various existing providers to participate in Medicare in a more appropriate way.

Thank you for this opportunity to express our views based on our experience as primary providers of terminal care.

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STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION

The American Hospital Association, which represents more than 6,300 member hospitals and health care institutions, as well as over 35,000 personal members, is pleased to have this opportunity to present its views and recommendations on H.R. 5180, a proposal to provide hospice care under the Medicare program.

Our Association has long been committed to increasing the scope of cost-effective, community-based health services and programs for the elderly and for those who are terminally ill. According to a 1981 survey conducted by the Joint Commission on Accreditation of Hospitals (JCAH), of the 440 known operational hospice programs

in the United States, 204 or 46 percent are hospital-based. Of these 204 hospital-based programs, 24 percent provide hospice home care services, 7 percent provide inpatient hospice services, and 69 percent provide a mixture of inpatient and home care hospice services.

Perhaps one of the most rapidly growing trends in care devoted to the dying patient in this country is the concept of hospice care. As the concept has evolved in the United States, hospice care has come to mean health care and services provided to terminally ill patients and their families that emphasize palliative and supportive care directed at allaying the unique physical and emotional discomfort associated with terminal illness. The care is planned and provided by a medically supervised interdisciplinary team composed of physicians, nurses, psychologists and counselors, the clergy, therapists, social workers, and volunteers. The orientation of hospice care is to organize all components of the terminal patients' and families' needs in a coordinated program of care. This program of care encompasses acute treatment care, skilled nursing facility or freestanding hospice care, and care in the home.

The fundamental dilemma in designing hospice programs is the need to maintain the philosophy of hospice care amid the economic realities of the health care delivery system. This requires acknowledging that health care resources are limited and that choices must be made to maximize the allocation of these resources. It also requires acknowledging that the large, established health care delivery system should be adapted to accommodate the hospice concept.

With this in mind, the Association commends the efforts of this Committee to begin discussions on the elements of appropriate and efficient hospice services and to provide for Medicare coverage of hospice services.

### MEDICARE COVERAGE OF HOSPICE SERVICES

*Summary of the bill*

H.R. 5180 would permit terminally ill Medicare beneficiaries (defined as those with a certified medical prognosis of less than six months to live) to elect to receive hospice benefits during two periods of 180 days each, in lieu of certain other curative Medicare benefits. Hospice programs are described as those provided by a public agency or private organization (or a subdivision thereof) which is primarily engaged in furnishinig hospice care directly or through arrangements with other hospice programs, as needed, on a 24-hour basis. Hospice services are defined as the following items and services, furnished by a hospice program under a written plan: nursing care; physical, occupational, or speech therapy; medical social services; home health aide and homemaker services; medical supplies; physicans' services; short-term inpatient care (including respite care and symptom management); and counseling services (including bereavement and dietary counseling). Under this bill, hospice services could be provided in the patient's home, on an outpatient or an inpatient basis. The hospice program could not provide more than 20 percent of its aggregate calendar days of care in an inpatient setting.

H R. 5180 also would require that the hospice have an interdisciplinary group of personnel including one or more physicians, registered nurses, social workers, and pastoral and other counselors. Central clinical records would have to be maintained. In addition, the hospice would be required to utilize volunteers in the provision of hospice care and to maintain records on the cost savings service expansion achieved through the use of such volunteers.

Medicare payment for hospice services would be limited to 75 percent of the average per capita Medicare expenditures for terminally ill cancer patients not under hospice care in a base period, adjusted for regional price variations, and annually indexed to the medical care component of the Consumer Price Index (CPI). Payment to an individual provider would be made on the basis of the reasonable costs of efficiently delivered hospice care or on the basis of such other test of reasonableness that the Secretary of HHS may define, up to the limit.

### AHA COMMENTS AND CONCERNS

We are committed to and support the objective of encouraging more coordinated, compassionate care for the dying patient. However, we would like to point out certain problems inherent in H.R. 5180 and suggest modifications which would be consistent with our objective.

The American Hospital Association commends the efforts of this Committee to begin discussions on Medicare coverage of hospice services. However, because the implications of federal support for hospice services are not yet known, we urge you to consider all of its aspects carefully. In 1979, the Congress mandated a study of the

implications of including hospice services under Medicare. This study, now in progress, is examining the impact of hospices on the quality of life of terminal patients and their families; the cost of hospice services versus traditional services; the likely impact of Medicare reimbursement on the organizational structure, staffing, and cost of hospice services; and the likely level of national utilization. The study is scheduled for completion in 1983. We believe it would be prudent to await completion of that study and a discussion of the results before the enactment of any legislation to provide Medicare coverage for hospice programs.

*Separate provider status*

Presently, hospice programs, including those that are hospital-based, participate in Medicare within existing provider classifications, such as hospital, skilled nursing facility, and home health agency. Medicare will pay for some of the services, such as physician services and skilled nursing; however, Medicare does not specifically cover hospice care as a distinct type of service. H.R. 5180 would permit Medicare reimbursement for hospice services only to hospices with separate provider status. This proposed separate provider status requirement presents a particular problem to hospitals and home health agencies. Inherent in separate provider status would be a requirement that hospital and home health agency hospices be established as a separate and distinct entity, which would subject these programs to separate and multiple survey and certification requirements. We are concerned that the separate provider status and the resulting separate survey and certification requirements would work as disincentives to hospitals and home health agencies wishing to provide hospice services, impede effective and efficient cooordination of care, and unnecessarily increase costs.

Under the proposal, hospitals choosing to provide hospice services would be subject to two, and possibly three, sets of Medicare certification requirements—the separate conditions of participation for hospitals, for home health agencies, and for hospice programs. Past experience of the AHA and its member hospitals indicates that such multiple certification requirements frequently result in additional administrative burdens and duplicative recordkeeping requirements for hospitals, and that they increase costs without improving the quality of care.

Wholly separate certification standards and surveys for different levels of care present two basic types of problems for hospitals which sponsor or provide several levels of care.

The first problem relates to the standards adopted under each of the certification programs. For example, if personnel standards under the certification programs differ, they impede an institution's ability to share staff. This variation in similar standards limits a hospital's ability to manage and reallocate resources between different levels of care when faced with a shortage of resources or low utilization in one of the levels of care. The ability to reallocate resources is a necessary element in holding health care costs down.

The second problem is the unnecessary burden and cost of multiple compliance surveys. Combined standards dictate combined surveys, conducted during a single site visit. Separate standards and certification programs lead to separate surveys for each level of care, conducted by separate inspection teams, scheduled at different times. Combined surveys consume less time, in the aggregate, than do separate surveys, thereby reducing disruption of patient care and administrative activities and reducing the potential for inconsistent surveyor interpretations of parallel standards.

In view of these types of problems, we urge you to eliminate the separate certification requirements for hospital and home health providers of hospice services. We believe that standards for quality hospice services can be incorporated in the existing Medicare conditions of participation for hospitals and home health agencies, and that such an incorporation would not only decrease administrative burdens, but also contribute to and enhance continuity of care.

*Program design*

The legislation would require a hospice program to be the locus for coordinating and managing all Medicare-covered care and services provided its patients. Such care would be provided directly by the hospice program in the patients' homes, or on an outpatient basis and on a short-term inpatient basis or through arrangements with other hospice programs. The hospice program would be responsible for the care provided under these arrangements. Further, the hospice program would be responsible for billing Medicare for all services provided by agencies with which it contracts, and contracting agencies would be required to bill the hospice program for services they provide to hospice patients. Therefore, the hospice program would have to be centrally administered.

We are concerned that the requirement that hospice services be provided directly by the hospice program or through arrangements with other hospice providers coupled with the separate provider status requirement disregards the existence of the current delivery system and would foster the development of a new freestanding hospice delivery system. Moreover, we believe the development of new provider organizations and institutional facilities would not contribute to the integration of services and continuity of care, principal goals of the hospice movement.

As demonstrated by the JCAH survey, hospitals are involved in the development of almost half of existing hospice programs. They have played a major role in the development of hospital-based inpatient units and hospital-based hospice home care programs. Moreover, hospice programs often originate in home care programs, freestanding or hospital-based, for which the most readily available facilities for inpatient hospice care are hospitals. Therefore, a system already exists which should be used as the foundation for hospice programs. We believe the establishment of separate hospice facilities would be both costly and duplicative, and we question whether this is the most appropriate and efficient use of health care dollars in the present economic environment. We believe that hospice care is part of the continuum of care and need not be provided by a separate entity.

Although some contend that new provider organizations are essential to the continuity of hospice service care, we believe that continuity can best be achieved by integrating hospice care in the existing system through the development of formal linkages between inpatient facilities and home health agencies. For example, linkages can be achieved through written agreements between the hospices program and other providers which delineate the services to be provided, the role of each agency or facility, and how services will be coordinated. We believe the legislation should permit hospices to utilize other providers in delivering hospice services.

Another way hospice care can be integrated in the existing system is through the involvement of the patient's attending physician. Facilitating physician acceptance of the concept of palliative versus curative care is fundamental to the hospice concept. However, we are concerned about the provision in the legislation that both the patient's attending physician and the hospice physician certify and recertify the need for hospice services, and that the hospice physician establish and review the written plan of care. Not only is this requirement duplicative, but it could disrupt the important relationship which exists between patients and their attending physicians.

*Covered services*

Because hospice care theoretically is geared to respond to the physical, spiritual, psychological, and social needs of the patient and family, the range of services in a hospice program is extremely broad. However, given the hospice concept of palliative care, we urge the Committee to carefully consider the appropriateness of mandating certain types of services. Moreover, we question the precedent of using Medicare trust funds to pay for services for individuals who are not Medicare beneficiaries. We believe the services offered under the Medicare hospice benefits must be appropriate to palliative care and should be focused on the patient.

*Payment standards and limits*

Medicare payment for hospice services would be limited to 75 percent of the average per capita Medicare expenditure for terminally ill cancer patients under hospice care in a base period, adjusted for regional price variations and annually indexed to the CPI. This limit appears to be based on an arbitrary determination of the relationship between the reasonable costs of inpatient acute and long-term care. We would urge that before enactment of the legislation, a study be completed to determine the proper relationship.

Our major concern is with the lack of a true standard for payment for hospice services. We believe the legislation should provide guidance to the HHS Secretary in establishing a payment methodology. Such methodology should take into account the total cost of providing hospice services.

## CONCLUSION

The American Hospital Association commends the efforts of this Committee to begin discussion on Medicare coverage of hospice services. We support the objectives of the hospice concept and offer our assistance in further refinement of this proposal. However, in order to better understand the implications of Medicare coverage for hospice services, we urge you to await completion of the hospice study before the benefit is enacted.

STATEMENT OF THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION, INC.

The American Occupational Therapy Association, Inc. (AOTA) appreciates the opportunity to submit this statment on H.R. 5180, a proposal to provide coverage of hospice care under the Medicare program, in conjunction with hearings held before the Subcommittee on Health of the Committee on Ways and Means on March 25, 1982.

The American Occupational Therapy Association, Inc. was formed in 1917 and represents over 33,000 occupational therapists, certified occupational therapy assistants, and students of occupational therapy. The Association manages the national certification system for occupational therapists; accredits occupational therapy educational programs in conjunction with the American Medical Association (AMA); has developed and directs a system of continuing educational opportunities for therapists throughout the country; and has established and monitors professional standards of practice and ethics. The Association also serves as a strong advocate and public voice for people of all ages who are physically, mentally or developmentally disabled and for those suffering from a terminal illness.

INTRODUCTION

The AOTA has long supported hospice care as an alternative to expensive, and sometimes dehumanizing, institutionalization for the terminally ill and we are pleased that hospice care is now receiving the Congressional attention it deserves. The present Medicare reimbursement system often forces treatment for the terminally ill into the most expensive, most intensive and often unwanted settings and in many cases ignores the needs and desires of the patient and his/her family.

The hospice concept is founded on the premise that a hospice will provide support and care for terminally ill patients and their families as they go through the dramatic life experience of progressive disease and ultimately the final stage of death. It should be stressed that hospice is a concept, not a specific setting. Though some hospice sponsors provide care in discreet units within hospitals or in freestanding facilities, it is the nature of the services and the underlying philosophy, not the setting, which distinguishes a hospice program from other approaches to terminal care.

The following principles set apart hospice care from the conventional lifesaving, prolonging alternatives offered by hospitals and long-term care facilities:

The patient and his/her family, not just the patient, are considered the unit of care.

An interdisciplinary team is used to assess the physical, psychlogical and spiritual needs of the patient and family, develop an overall plan of care and provide coordinated care, including occupational therapy.

Pain and the collateral symptoms associated with the terminal illness and its previous treatment are controlled, but no heroic efforts are made to cure the patient.

The patient has freedom of choice in his/her treatment and setting.

Bereavement follow-up is provided to the family to help them cope with their emotional suffering.

The program's objective is to ensure that the terminally ill patient is given the opportunity to live out his/her remaining days as comfortably, meaningfully and independently as possible in dignity and peace. The real purpose is to add life to the patient's remaining days, not add days to the patient's remaining life. Occupational therapy can contribute substantially to the achievement of this goal.

There is a general consensus that hospice care is a necessary, humane and valuable program and all studies to date have indicated that establishing hospice centers as providers under Medicare would be very cost-effective. This is an excellent example of how well developed alternative Medicare benefits, with no increase in beneficiaries, can result in improved health care at reduced costs. Although the Health Care Financing Administration (HCFA) has not yet completed its Medicare hospice demonstration project (due later this year), the demonstrated need and value of hospices taken in conjunction with presently available data provide a basis to proceed with the program now. The results of the Health Care Financing Administration study, if contrary to present data, can serve to later adjust the program as needed.

The American Occupational Therapy Association strongly supports the inclusion of hospice care under the Medicare program and we are confident that an increase in this type of care will result in savings to Medicare. In addition, occupational therapy is an integral part of hospice care and we urge that occupational therapy continue to be specifically identified as a service to be provided to the Medicare beneficiary under a hospice program as presently incorporated in H.R. 5180. It should be noted that the inclusion of occupational therapy will not result in any additional

occupational therapy services being provided to the Medicare patient, but rather that needed occupational therapy services will be made available in an alternate, and less expensive, setting.

The Congress has received substantial data and information on hospice care in general and on the cost-savings to Medicare. The remainder of our statement, therefore, is devoted to the practice of occupational therapy and to the role of occupational therapy in hospice care.

### THE PRACTICE OF OCCUPATIONAL THERAPY

Occupational therapy is a health profession which has its foundation in the medical management of patients. The service is provided to persons of all ages who are physically, paychologically, or developmentally disabled. It includes the functional evaluation and treatment of several different types of patients including those suffering from cancer, strokes, heart attacks, arthritis, diabetes, serious burns, spinal cord injuries, and psychiatric disorders. The purpose of occupational therapy is to direct these patients to achieve a maximum level of independent living by developing those capacities which remain after disease, accident, deformity, or the onset of a terminal illness.

The occupational therapist's initial focus is on treating that pathology or those impaired functions which preclude independence and productivity. Occupational therapists evaluate and treat:

Impaired muscle strength, range of motion, and physical endurance;

Impaired eye-motor coordination, sensory integration, and motor planning;

Impaired concentration, attention span, thought organization, and problem solving; and

Impaired visual-spatial relationships, body schema, figure-ground discrimination.

Occupational therapists also seek to inhibit muscle atrophy, minimize deformity, and increase pain tolerance. They are also vitally concerned with the paychological impairments which frequently result from the patient's illness or trauma.

The treatment modalities used by occupational therapists are those which, in addition to reducing specific pathology or impairment, will simultaneously help the patient learn to apply the newly restored or impaired function to the demands of daily living, thus speeding recovery and an early return to a more independent life.

In summary, occupational therapists use selected rehabilitative tasks to reduce specific pathology or impairment and help individuals achieve independence.

Occupational therapista provide services in rehabilitative centers, hospices, through home health agencies, in acute care hospitals, long and short-term psychiatric facilities, skilled nursing facilities, outpatient clinics, community mental health centers, tuberculosis hospitals, day care centers, and private and public school systems.

Occupational Therapists, Registered (OTRs) carry professional and administrative responsibilities for occupational therapy programs and services. They are responsible for evaluation patients, developing program goals, working with patients to achieve these goals, and documenting progress. Certified Occupational Therapy Assistants (COTAs), Working under the supervision of OTRs, assist in patient treatment and total program implementation.

### THE ROLE OF OCCUPATIONAL THERAPY IN HOSPICE CARE

The occupational therapists' education and training in the psychological and biological sciences allows them to make a valuable contribution to the psychosocial and functional needs of the hospice patient. The occupational therapist's role is supportive of and complementary to the other members of the hospice team. The occupational therapist serves as a member of the interdisciplinary hospice team and provides consultation and direct services as indicated by the needs of the patients.

Hospice programs in hospitals and nursing homes usually obtain occupational therapy services through the facilities' existing occupational therapy department. Home care hospice programs may be a unit of a home health agency and occupational therapy services are provided through the home health agency.

The occupational therapist utilizes a holistic approach to assess the patients' physical and psychosocial level of function and his specific needs and interests. Some patients may be very passive and others may want to remain active and as independent as possible until their death. Therefore, the occupational therapist designs each treatment program individually to address the individual needs of the patient and his family, as well as his/her capabilities and desires.

Patients admitted to hospice programs range from being completely independent to requiring intensive medical care. Therefore, the role of the occupational therapist

varies from simply establishing a rapport and discussing the occupational therapy services available, to evaluating the patients' needs and implementing a treatment program of supportive therapeutic activities and/or activities of daily living skills. The initial intervention of the occupational therapist may be brief, but the therapist will continue to monitor the patients' condition. As significant changes in function occur, due to the progression of the illness, the therapist re-evaluates and modifies the goals and treatment.

The majority of hospice patients perfer to die in their homes where they can remain close to their family in a supportive and caring environment. Occupational therapists treating home care patients focus on teaching these patients and their families specific activities of daily living such as feeding, self care, and transfers to promote and maintain the patients' level of independent functioning, thus allowing them to remain in their homes with their families. The occupational therapist instructs patients in methods of energy conservation and work simplification to assist them in preserving their strength and organizing their daily activities in a manner which will not cause stress or fatigue. Adaptive equipment and orthotic devices are also provided to enhance the patients' ability to function more easily within the limitations of his/her illness and disability.

The goal of the occupational therapists working in hospice care is to make the patients' remaining days as independent, comfortable and meaningful as possible and assist the family in coping with the stress of a terminal illness. Occupational therapists support the holistic approach and supportive caring environment of hospice care which is similar to the philosophy of occupational therapy. Occupational therapists believe hospice care has an essential role in providing the terminally ill and their families with a viable alternative to the traditional system of health care.

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AMERICAN PHYSICAL THERAPY ASSOCIATION,
*Washington, D.C., March 31, 1982.*

Hon. ANDY JACOBS, Jr.,
*Chairman, Subcommittee on Health, Committee on Ways and Means, U.S. House of Representatives, Washington, D.C.*

DEAR MR. CHAIRMAN: The American Physical Therapy Association (APTA) representing almost 40,000 physical therapists nationwide, welcomes this opportunity to submit this statement for the record of the hearing held on Thursday, March 25, 1982, on H.R. 5180, a bill to provide coverage of hospice care under the Medicare program.

It is the position of the APTA that hospice care should be available as an alternative to institutionalization for those patients and families who prefer this emerging concept of care for the terminally ill. There are several reasons which prompt our support.

The record is replete with testimony to the effect that a program of hospice care is effectively tailored to the needs of the terminally ill, and, as such, is uniquely able to provide the patient with services and support which do not readily lend themselves to provision in the institutional setting. Furthermore, the support that is made available to the members of the family is an equally important and integral part of hospice care.

In times such as these, when budget austerity is of the essence, hospice care represents a demonstrably cost effective mode of delivery of care. The terminally ill patient benefits little from the provision or availability of intensive medical care which lies at the core of institutionalization. Therefore, this alternative, which is often the route taken, represents little more then a highly expensive and ineffective method of treatment. Rather than encouraging this inefficiency by rigidly adhering to a reimbursement mechanism which does not recognize the more effective alternative of hospice care, we urge the Congress' favorable consideration of H.R. 5180.

Physical therapists are an integral part of the interdisciplinary team whose service amount to an effective program of hospice care. Physical therapists are uniquely trained to provide exercises that help maintain endurance and mobility and to educate the family to participate in transfer and hygiene activities. Moreover, physical therapists are trained in the use of modalities, particularly transcutaneous electrical nerve stimulation, to provide the patient with alternative means of pain control. All of these activities have as primary goals reduction of pain and discomfort, maintenance of the patient's independence for as long as possible, and the safety of the patient and family.

Consequently, as an association whose membership is adept in the provision of a number of the services which constitute hospice care, the APTA supports legislation

such as H.R. 5180 which recognizes the desirability of making quality and cost effective care available in the most efficient manner.

Sincerely,

R. CHARLES HARKER, Esq.,
*Director of Government Affairs.*

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STATEMENT OF DR. MARCUS E. DREWA, CHAIRMAN OF THE BOARD, AMERICAN PROTESTANT HOSPITAL ASSOCIATION, AND PRESIDENT, METHODIST HOSPITAL AND METHODIST HOSPITAL FOUNDATION, JACKSONVILLE, FLA.

Mr. Chairman, thank you for this opportunity to submit my testimony regarding the Hospice Reimbursement Act (H.R. 5180) to the Subcommittee on Health of the House Ways and Means Committee.

As President of Methodist Hospital and Methodist Hospital Foundation, Jacksonville, Florida, I have been committed to and involved in the planning, development, and implementation of hospice services since 1978.

Methodist Hospice of Jacksonville is a comprehensive hospice program of care including an 18-bed inpatient unit, a 5-county hospice home care program, and a bereavement counseling service. Methodist Hospice serves the Northeast Florida area, including the highly-dense population area of Jacksonville and sparsely-populated rural counties which are medically-underserved by federal and state standards.

Methodist Hospice functions as a self-standing alternative program of care to the already-existing acute and chronic care system in our community. Ours was the first hospice licensed in Florida, the first hospice to receive a certificate of need in our state, and the first to be surveyed by quality-control agencies for compliance with appropriateness and quality criteria.

Our program functions in accordance with the standards and principles of the National Hospice Organization. While Methodist Hospice is hospital-based, it is governed by its own hospice board, has a hospice administration, employs a discreet hospice staff including Medical Director and Associate Medical Director, and is housed separately from the hospital in a building on the medical center campus. The inpatient unit functions in a home-like fashion, free from the restrictions typical of acute care settings. Patients are given free choice of diet, parlors and kitchen facilities are provided on the hospice unit, living rooms and space for families to stay overnight are on the same floor, and rooms are over-sized and comfortably furnished with decor reminiscent of patients' own homes. There are no visiting restrictions and children and pets are freely permitted. The home care program provides 24-hour, 365-day scheduled and unscheduled care by physicians, nurses, aides, counselors, clergy, social workers, and volunteers.

Based upon our experience, the follow conclusions are appropriately drawn:

1. The existence of a distinct part, separately-functioning hospice inpatient unit is of substantial impact in assuring that hospice becomes an alternative form of care as opposed to an "add on" service.

2. The management of hospice patients at home directly by the hospice team, itself, instead of referring or subcontracting such care to a nonhospice organization leads to the ability to be in control of home care with the result of being able to more effectively avoid unnecessary institutionalizations.

3. The existence of the Hospice Medical Director as a direct caregiver in the inpatient setting and in patients' homes, as opposed to a distant "medical adviser" who does not see patients regularly, is of primary importance in assuring not only the quality of care but the appropriate use of services so as to avoid hospitalization.

As Chairman of the Board of the American Protestant Hospital Association, I am painfully aware of the national reimbursement dilemma regarding hospice. It is a tragic fact that many dying Medicare beneficiaries who might otherwise need and want hospice care are, instead, receiving aggressive medical therapies desired, really, by neither the patient/family nor the physician. However, in the absence of hospice, aggressive therapy is employed in order to "do something" for the patient. The other side of the dilemma is that nonprofit institutions and organizations, particularly within the religiously-affiliated health sector in America, are faced by the existing Medicare system with a strong disincentive to fulfill their desires to offer the hospice alternative. By not providing recognition of comprehensive hospice care, as such, under Medicare, the tendency is to either try to skew hospice into existing reimbursement catagories (which leads to over-utilization of covered services and under-utilization of less-expensive uncovered services) or, more likely, to non-development of hospice care.

Responsible hospitals cannot help but look at the hospice alternative as a mission and ministry worthy of offering. Our hospital and foundation in Jacksonville have worked exceedingly hard to find community charitable dollars to support the delivery of hospice care to the poor. We pledge to continue and to intensify our efforts to preserve and extend the voluntary fund-raising and voluntary care-giving character of hospice. However, it is an artificial disincentive that is certainly not in the government's interest to retain the existing reimbursement system that does not fully reimburse hospice costs as hospice costs.

It can be fairly said that failure to pass H.R. 5180 would be a conscious decision by the Congress to skew hospice into the more-costly, acute care mode within hospital-based hospices while actively stifling the offering of the hospice alternative.

Simply changing the existing Medicare laws and regulations to permit hospitals to more easily obtain reimbursement for palliative care would neither be in the interest of dying patients nor in the interest of the legitimate, bona fide hospital-based hospices in our country. Only a seperate reimbursement catagory fully recognizing the uniquness and integrity of the hospice program as an alternative form of care should be enacted by the Congress.

There is ample evidence that such a comprehensive approach to hospice services will result in comparative cost savings to the Medicare Trust Fund. As part of my testimony I include a study of Methodist Hospice's first 183 patients, admitted from June through December of 1980.

It would be by permitting hospices to be literal brokers of services or general contractors existing to feed sub-contractors that hospice would be an "add on" cost to the Medicare system.

As President of Methodist Hospital-Methodist Hospital Foundation and as Chairman of the American Protestant Hospital Association, I urge you to pass H.R. 5180 as the best guarantee of the integrity of the hospice concept and the best delivery mechanism for hospice services.

Without hospice reimbursement as empowered under H.R. 5180, hospice will be less and less economically feasible for hospitals to plan or provide as an alternative. With the passage of H.R. 5180, hospice can take its rightful place as a cost-effective, compassionate, competent form of care for the terminally ill and their families.

Thank you, Mr. Chairman.

[Attachments]

PURPOSE OF THE STUDY

Methodist Hospice began operation of its comprehensive inpatient, home care, and outpatient hospice program on June 4, 1980. For fifteen months prior to that date, home care services only were being provided to terminally ill patients as part of the overall services of ABC Home Health Services, managed by Methodist. However, it is from June 4, 1980, that Methodist dates the establishment of bona fide hospice care in a comprehensive sense.

During the first seven months of the program, one hundred eighty-three terminally ill persons were admitted into hospice care and died during this period. The financial and insurance records of these patients are studied in this report in order to determine:

Measurements of the financial charges made for services rendered to these patients.

Average charges for various components of the hospice program such as inpatient care and home care.

Variances in charges for patients requiring primarily inpatient care as opposed to patients primarily able to be cared for at home.

Comparisons in lengths of stay and charges with patients of similar diagnoses cared for in general hosptial settings in this community. (Utilizing a study concluded prior to the opening of the Methodist Hospice program).

This study was accomplished by James Langley, Jr., administrative resident at Methodist Hospice, under the direction of Donald J. Gaetz, vice president of Methodist Hopstial and administrator of Methodist Hospice.

CHARACTERISTICS OF PATIENTS STUDIED

One hundred eighty-three patients were studied. These patients were admitted into the hospice program by one hundred fourteen physicians, of which seventy-two were not members of the Methodist Hospice medical staff and forth-two were members of the staff.

Sixty-six precent or one hundred twenty-one patients were Medicare patients. Three percent or six patients were Medicaid patients. Twenty-four percent or forty-four patients had some private insurance while six percent or twelve patients had no insurance or third party payment whatsoever.

Ages ranged from twelve to ninety-three. Ninety patients were males. Ninety-three patients were females.

Fifty-eight of these persons had the primary diagnosis of cancer of the respiratory tract. Thirty-two had primary cancer of the gastro-intestinal tract. Sixteen had primary cancer of the breast. Twelve females had primary cancer of the reproductive organs while seventeen males had primary cancer of the reproductive organs. Thirty patients had cancer in other primary sites while eighteen patients primarily suffered from cardiac, pulmonary, cerebro-vascular, A.L.S., or sclerosis conditions. Slightly over ninety percent of the patients studies suffered from cancer.

Sixty-four percent of these patients were made known to the hospice program initially by their attending physicians while twenty-one percent initially made themselves known to the hospice either personally or through a family member or friend. Ten pecent were initially referred by hospitals and five percent by home health agencies. One hundred percent were admitted by their attending physicians.

### FINANCIAL CONCLUSIONS—EXPLANATION OF GROUPINGS

For the purposes of this study, Medicare/Medicaid patients were considered together in Group A. Private pay/private insurance/total charity patients were considered together in Group B. This was done in order to isolate for comparison those patients whose hospice services were covered by Title 18 insurance.

Group A includes one hundred twenty-one Medicare patients and six Medicaid patients.

Group B includes forty-four patients who had some private insurance or made some private payments and twelve patients who made no payments whatsoever and had no coverage of any kind.

## MEDICARE/MEDICAID HOSPICE PATIENTS

[Summary sheet—Group A]

| | Single admission, inpatient and home care | Multiple admissions, inpatient and home care | Inpatient only | Home care only | Totals/average |
|---|---|---|---|---|---|
| Number in program | 31 | 15 | 62 | 23 | 131.00 |
| Number in inpatient admissions | 31 | 40 | 62 | ..... | 133.00 |
| Total term of care days | 1,127.00 | 1,120.00 | 712 | 824 | 3,783.00 |
| Average number of days in program | 36.35 | 74.66 | 11.48 | 35.82 | ..... |
| Total charges | $54,326.00 | $85,484.00 | $30,868.00 | $14,866.00 | $285,544.00 |
| Program per diem charges | $48.20 | $76.32 | $183.80 | $18.04 | ..... |
| Average charge per patient/family | $1,752.45 | $2,137.10 | $2,110.77 | $646.34 | ..... |
| Total inpatient charges | $42,019.00 | $78,093.00 | $130,868.00 | ..... | $250,980.00 |
| Total number of inpatient days | 219.00 | 432.00 | 712.00 | ..... | 1,363.00 |
| Average length of inpatient stay | 7.06 | 10.80 | 11.48 | ..... | 10.24 |
| Average charge per inpatient day | $191.86 | $180.77 | $183.80 | ..... | $184.13 |
| Average charge per inpatient admission | $1,355.45 | $1,952.32 | $2,110.77 | ..... | $1,887.06 |
| Total home care charges | 12,307.00 | 7,391.00 | ..... | 14,866.00 | 34,564.00 |
| Total number of home care days | 908.00 | 688.00 | ..... | 824.00 | 2,420.00 |
| Total home care visits | 427.00 | 263.00 | ..... | 474.00 | 1,164.00 |
| Average number of home care visits per patient | 13.77 | 17.53 | ..... | 20.60 | 16.86 |
| Average home care per diem | $13.55 | $10.74 | ..... | $18.04 | $14.28 |
| Average charge per home care visit | $33.90 | $34.05 | ..... | $32.81 | $33.45 |
| Number of nursing visits [1] | 259 (60) | 161 (61) | ..... | 237 (50) | 657 (56) |
| Number of volunteer visits [1] | 64 (14) | 46 (12) | ..... | 21 (04) | 131 (11) |
| Number of physician and other visits [1] | 104 (24) | 56 (21) | ..... | 216 (45) | 376 (32) |

[1] Figures in parenthesis represent percent.

## PRIVATE PAY/PRIVATE INSURANCE/TOTAL CHARITY HOSPICE PATIENTS

[Summary sheet—Group B]

| | Single admission, inpatient and home care | Multiple admissions, inpatient and home care | Inpatient only | Home care only | Totals/average |
|---|---|---|---|---|---|
| Number in program | 15 | 4 | 23 | 10 | 52.00 |
| Number of inpatient admissions | 15 | 8 | 23 | | 46.00 |
| Total term of care days | 566.00 | 250.00 | 271.00 | 457.00 | 1,544.00 |
| Average number of days in program | 37.73 | 62.50 | 11.78 | 45.70 | |
| Total charges | $32,642.00 | $9,368.00 | $51,988.00 | $5,895.00 | $99,893.00 |
| Program per diem charges | $57.67 | $37.47 | $191.83 | $12.89 | |
| Average charge per patient/family | $2,176.13 | $1,171.00 | $2,260.34 | $589.50 | |
| Total inpatient charges | $26,927.00 | $5,957.00 | $51,988.00 | | $84,872.00 |
| Total number of inpatient days | 150.00 | 26.00 | 271.00 | | 447.00 |
| Average length of inpatient stay | 10.00 | 3.25 | 11.78 | | 9.71 |
| Average charge per inpatient day | $179.51 | $229.11 | $191.83 | | $189.87 |
| Average charge per inpatient admission | $1,795.13 | $744.62 | $2,260.34 | | $1,845.04 |
| Total home care charges | $5,715.00 | $3,410.00 | | $5,895.00 | $15,020.00 |
| Total number of home care days | 416.00 | 224.00 | | 457.00 | 1,097.00 |
| Total home care visits | 175.00 | 122.00 | | 184.00 | 481.00 |
| Average number of home care visits per patient | 11.66 | 30.50 | | 18.40 | 16.58 |
| Average home care per diem | $13.73 | $15.22 | | $12.89 | $13.69 |
| Average charge per home care visit | $42.02 | $32.78 | | $37.31 | $37.73 |
| Number of nursing visits [1] | 105 (60) | 54 (44) | | 105 (57) | 264 (54) |
| Number of volunteer visits [1] | 19 (10) | 18 (14) | | 26 (14) | 63 (13) |
| Number of physician and other visits [1] | 51 (29) | 50 (40) | | 53 (28) | 154 (32) |

[1] Figures in parenthesis represent percent.

## INSURANCE COVERAGES

| Insurances | Single admission inpatient and home care | | Multiple admission inpatient and home care | | Inpatient only | | Home care only | | Totals, average | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Medicare | 26 | 56 | 13 | 68 | 60 | 70 | 22 | 66 | 121 | 66 |
| Medicaid | 1 | 2 | 2 | 10 | 2 | 2 | 1 | 3 | 6 | 3 |
| Other | 16 | 34 | 4 | 21 | 17 | 20 | 7 | 21 | 44 | 24 |
| None | 3 | 6 | | | 6 | 7 | 3 | 9 | 12 | 6 |

### COMPARISON TO PATIENTS STUDIED IN 1978

In December of 1978, a study was made of terminally ill cancer patients cared for at Methodist Hopsital between July, 1973, and June, 1978. Specific analysis was done on the cases of sixty-one patients cared for at Methodist between January and June of 1978 who met all criteria for admission to a hospice program of care, had there been such a program in existence at that time.

These sixty-one patients accounted during the last month of their lives for an average of 22.23 hospital inpatient days each or a total for the group of 1,356 hospital days.

By comparison, the hospice patients in Group A accounted for an average of 10.24 inpatient days each. Hospice patients in Group B accounted for an average of 9.71 inpatient days each.

The average charge per patient in the 1978 study was $6,179.80 based upon hospital per diem of $278. This includes no physician, home care, or outpatient charges.

The average charge for Group A hospice patients ranged from $646.34 (home care patients only) to $2,137.10 (multiple inpatient admissions plus home care). The average hospice program per diem for this group range from $18.04 (home care patients only) to $183.80 (inpatients only).

The average charge for Group B hospice patients ranged from $589.50 (home care patients only) to $2,260.34 (inpatients only). The average hospice program per diem for this group ranged from $12.89 (home care patients only) to $191.83 (inpatients only).

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AMERICAN PSYCHIATRIC ASSOCIATION,
*Washington, D.C., April 1, 1982.*

Hon. ANDREW JACOBS,
*Chairman, Subcommittee on Health, House Commmittee on Ways and Means, Washington, D.C.*

DEAR MR. CHAIRMAN: The American Psychiatric Association, a medical specialty society representing over 26,000 psychiatrists nationwide, understands the constraints which did not permit us to testify in person and is pleased to submit for the hearing record our comments on H.R. 5180 which would establish Medicare reimbursement for hospice care.

The APA believes that the hospice is an important concept in the care of patients whom medical science and technology can no longer help either become well or be maintained at a particular stage of illness and provides a humanitarian way for the terminally ill patient to approach death with dignity, in relative comfort, in a supportive atmosphere and in the presence of family members.

The emphasis in a hospice is appropriately placed on care, not on cure, comfort rather than rehabilitation. Active therapeutic treatment is no longer pursued, nor is it deemed appropriate.

The APA commends the hospice movement as a humanitarian alternative for the terminally ill, particularly in view of its emphasis on the quality of life, for living comfortably until death, for the absence of pain and the maintenance of personal control over one's destiny. However, we believe there are a host of unresolved public policy questions which are engendered in the legislative proposal now before the Subcommittee, some of which may well impact upon the push and pull, apparent at the hearing, with respect to actual cost versus cost savings associated with this legislation. A number of these policy questions are general in nature; others pertain specifically to the "counseling services" intended to be provided under the legislation.

Among the questions which we believe need answers before this legislation is adopted and some of which may be answered by the ongoing HCFA demonstration include:

How will the model of hospice care (home, hospital or other facility based) affect the costs associated with the program?

Should there be a medical necessity standard to determine the appropriateness of utilization of the hospice benefits' non-medical services?

Is the bill encouraging the development of a proprietary facility movement rather than the growth of the hospice system with an emphasis on voluntarism and nonprofit activity?

Of deep concern to the APA are the so-called "counseling services," particularly as they are juxtaposed to current Medicare coverage for phychiatric disorders.

We do not understand the bill establishing a public policy of unlimited counseling services reimbursement for the hospic-based terminally ill patient when that benefit is not available to terminally ill patients needing such services but not receiving care in a hospice environment. Why is this class of patient selected to receive unlimited counseling services when Medicare tragically continues to limit outpatient medically necessary psychiatric care to $250 per year and inpatient psychiatric care to a 190 day lifetime limit for all other Medicare-eligible patients.

Further the legislation authorizes a non-Medicare eligible family member of a hospice patient to receive "bereavement counseling" paid for by Medicare, yet such services are not available to the similarly grieved family member of a terminally ill Medicare patient who dies outside the hospice system. We do not oppose expanding the coverage to bereaved family members, but would first urge Congress to eliminate the discriminatory and selective restrictions placed upon the availability of medicaly necessary psychiatric intervention for the current Medicare recipient. We believe that if a broadening of reimbursement for the Intervention in nervous, mental or emotional disorders, in which we include the grieving process, is intended, it would more appropriately be directed toward meeting the health care needs of current Medicare recipients in need of such treatment. This would prove an enlightened recognition of the study after study which document the cost-effective feature of such medical intervention (a brief overview of some of these studies is appended to this letter).

We are equally concerned that no medical necessity standard would be required for family-member counseling services. Further, there would be no requisite for medical supervision, an important element in determining the nature and extent of counseling required. (We are pleased to note, however, that such medical direction is required for counseling and social services provided directly to the hospice patient.)

Bereavement counseling provided to a Medicare-eligible family member should be medically necessary (and apply as well to non-hospice related medicare recipients) to allow as many medically necessary visits as are required to alleviate the particular individual's suffering as the result of his or her loss. Similarly, we would hope that the current restrictions upon Medicare's psychiatric treatment reimbursement which compels us to address these matters, can be eliminated so Medicare recipients with a nervous, mental or emotional disorder—not just the grieving associated with the loss of a loved one who happended to die in a hospice—can receive a full range of medically necessary psychiatric treatment. The legislation, while silent on the issue, we trust, does not further intend to penalize the Medicare recipient who utilizes such counseling services when a loved one dies by off-setting the use of such services against their existing restricted outpatient or inpatient psychiatric Medicare benefit.

We believe the hospice concept has merit, but the immediate response, as suggested in the bill pending before the Subcommittee, fail to address many basic health policy questions which will directly affect the medical needs of the Medicare recipient suffering from mental illness.

We appreciate your making this letter and its attachments part of the hearing record.

Sincerely,

MELVIN SABSHIN, M.D., *Medical Director.*

Enclosure.

PSYCHIATRIC BENEFITS IN HEALTH INSURANCE

As early as 1974, the National Institute of Mental Health estimated that the indirect costs of mental illness were close to $20 billion. The study noted that "Indirect costs are the income or income-equivalent losses which result from deaths due to mental illness, total disability due to mental illness and the loss of productive time to those individuals . . ." (1) Moreover, such costs do not reflect "all losses associated with partial disabilities, with pain and suffering not fully reflected by lost earnings, with homicides in the population not treated for mental illness and with the excess death incidence among those who have a history of mental illness but received no care." (2) Indeed, NIMH noted that the cost might well have doubled to $40 billion, in one year alone, if such above-mentioned factors had been included.

The cost-benefit and medical effectiveness of psychiatric services for patients with mental disorders in the general health sector are demonstrated in a substantial body of research (3) and show that notwithstanding other arguments to the contrary, psychiatric benefits are insurable; that they save other health care costs; and that they help make up the lost dollars of productivity.

Blue Cross of Western Pennslyvania studied the medical/surgical services utilization of a group of subscribers to whom mental health services were made available and that of a comparable group to whom they were not. The findings showed a significant reduction in the medical/surgical utilization for the group with psychiatric benefits as compared to the group without these benefits. The monthly cost per patient for all medical services was more than halved—dropping from $16.47 to $7.06. This cost savings substantially exceeded the costs of providing the psychiatric care. (4)

A longitudinal study carried out in a single Texas county from 1973 to 1977 showed that access to treatment for mental illness in inpatients over age 65 resulted in a reduction in mean length of stay from 111 days to 53 days and a cost savings of more than $1.1 million. (5)

A Kaiser Permanente study compared two matched groups of 152 patients each, one of whom received psychiatric intervention (study group) and one of whom did not (control group). Both groups initially were similar in their rates of general health care services utilization. Over a five-year period, the control group showed essentially no change in general health care utilization while, in sharp contrast, the study group experienced a reduction in its non-psychiatric outpatient visits by 62 percent, and in its inpatient days by 68 percent. (6, 7)

The Group Health Association of Washington reported that patients treated by mental health providers reduced non-psychiatric physician usage within the HMO

by 30.7 percent in the year after referral for mental health care was made available, compared to the previous years. In addition, there was a 29 percent decrease in laboratory and X-ray services. (8)

The Kennecott Corporation found that in a study of 150 men who received needed psychotherapeutic services, there was an estimated 6 to 1 benefit-to-cost ratio as a result of the program, and recorded a 52 percent attendance improvement and a 74.6 percent decrease in medical/surgical utilization costs after the psychotherapeutic services. (9)

In a West German study involving more than 1,000 patients with primarily chronic symptoms, it was found that in the five years following the availability of psychiatric services, the average annual number of hospital days per patient declined from an estimated 5.3 days to 0.8 days. (10)

A recently completed study compared 24 elderly patients who had undergone surgery for repair of hip fractures and had liaison psychiatric services with a similar group of 26 patients who had the same kind of surgery but did not receive the liaison services. The group receiving psychiatric liaison care required an average of 12 days less hospitalization resulting in an estimated savings of $193,000 or almost twenty times the cost of the psychiatric liaison services. Moreover, twice as many patients who had psychiatric liaison services were able to return home (rather than to nursing homes or other less cost-effective institutional settings). (11)

The introduction of lithium as a medically indicated psychiatric treatment for manic depression has accounted over the past ten years for a $2.88 billion savings in direct mental health costs and an additional $1.28 billion in productivity. (12)

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STATEMENT OF THE CALIFORNIA HOSPITAL ASSOCIATION

On behalf of the California Hospital Association, we would like to present our comments and recommendations on H.R. 5180 which would make hospice care reimbursable under the Medicare program. We want to commend this Committee for conducting these important hearings and to express our willingness to work with you to further this legislation.

Hospice care is not only a humanitarian approach to meet the needs and preferences of terminally ill patients, but can also represent a cost-effective alternative to care provided in an acute care hospital. Hospitals are increasing their involvement

in and support of hospice programs in California, and we believe such hospital participation can offer important advantages to advance this form of alternative care delivery.

CHA supports expansion of Medicare coverage to include certain services provided in the home and for respite services when provided under the auspices of an organized hospice program. Medicare should assure coverage of services for patient with terminal illnesses, who require palliative treatment or whose program of care requires medical direction. Medicare coverage would be important in the educational effort aimed at changing the orientation of physicians and hospitals with respect to the alternatives available for care of terminally ill patients.

In our review of H.R. 5190, as introduced, we have noted provisions in the legislation which we would like to recommend for possible modification.

First, the bill's definition of a hospice program states that the sponsoring organization must be "primarily engaged" in providing the covered hospice services. In our opinion it would be beneficial if this definition were less restrictive. Since it is our understanding that you do not wish to prohibit hospital sponsorship of hospice be eligible to provide hospice services under conditions applied to other public or private organization. Permitting hospital participation would help to improve the accessibility of beneficiaries to these services, and perhaps equally important, could provide a catalyst for the appropriate referral of patients by hospital personnel to this alternative.

A second point pertaining to the introduced measure is the matter of payment for required hospitalization once a patient has elected hospice care. Since the bill anticipates that the arrangements for hospital care will be made through organizations which do not offer inpatient care, it requires that payment for such services be made by the hospice agency to the hospital. As a result of the overall payment constraint under which hospice programs will operate, it is not clear on what basis or by what methods hospice organizations will arrange for and pay for needed hospital care. In any event reimbursement negotiations between hospices and hospitals seems an unnecessary and cumbersome complication. For administrative simplicity and efficiency, we recommend that hospital care furnished to hospice patients be reimbursed in the same fashion as would hospital care provided for other Medicare beneficiaries.

While we have drawn you attention to two technical issues in the introduced bill, we want to emphasize our support for the purpose of this legislation. This bill, in our opinion, combines a desirable social policy with a reasonable and fiscally responsible modification to the Medicare program.

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STATEMENT OF ELMER CERIN, WASHINGTON, D.C.

Mr. Chairman and Members of the Subcommittee on Health of the Ways and Means Committee, it is a pleasure to present this statement regarding H.R. 5180, the proposed Hospice Care Reimbursement Act. My name is Elmer Cerin and this statement is presented in my own behalf and not as a representative of any organization or association.

Mr. Chairman, I would first like to explain my personal interest in the hospice program. Two years ago my wife died after having suffred with amyotrophic lateral sclerosis (ALS) for three years. ALS, commonly called Lou Gehrig's disease, is a neurological disorder for which medical science has not yet discovered the cause, prevention, treatment of cure. ALS is a terminal illness which strikes during the top-productive years, in the 30 to 60 years of age range. From the outset, the disease follows a relentless course of progressive deterioration. The muscles of the body atrophy until the ALS patient is completely paralyzed and must live on a life-support system to survive. About 80% of the ALS patients die within two to four years after diagnosis; the remaining 20% survive for another few years. There are no known remissions.

For the first two and one-half years I took care of my wife at home, at first by myself. Subsequently, when additional assistance became necessary, I engaged one nurse's aide and for the last year at home I utilized two nurse's aides, both of whom I trained as to lifting and other procedures. I personally covered the costs for this nursing service as well as for the necessary equipment and medication. For the last year at home, these costs came to over $20,000, exclusive of my own long hours.

In the third year of her illness, I realized that my wife had only a few more months to live. Taking care of her had become extremely difficult and all-consuming. At that time, hospice was a new program and was limited to terminal cancer patients. I was, therefore, compelled to seek other assistance. By the payment of a

substantial contribution and in consideration of other factors, I was able to have my wife admitted to what is considered the best nursing home in the Greater Washington Area.

From the beginning, I spent 8 to 15 hours daily at the nursing home taking care of my wife. I, thus, soon became very familiar with the functioning of the facility. I spent long hours in the nursing home because I recognized that the level of care that my wife required could not be met by the staff alone. In addition to my services, I employed two private duty nurses for the evening and night hours.

While the physical plant of the nursing home was excellent, the level of care for the very sick was woefully inadequate. There was not enough well-trained and compassionate paraprofessional personnel on the floor. Moreover, to add to the inadequate staff, the turnover of nurse's aides was very high. Because of this fact, the traning program was minimal and new personnel were brought on the job with little or no training. In addition, from personal observation I had concluded that the supervision was both incompetent and superficial. This situation is probably the result of a fundamental difficulty facing nursing homes, namely, the professional and paraprofessional personnel are working in an atmosphere of despair in which they know that there is not too much that can be done. While, in some rare instances, tender loving care and personal attention were given, to most of the employees the job was dirty, poorly paid and unpleasant.

There were many other problems but two, in particular, deserve mention. There is an enormous overuse of medication to tranquilize the patients and, thus, make the tasks somewhat easier for the nurses and nurse's aides. For many hours of each day most of the subdued patients sit, zombie-like, in the television room completely oblivious to the flickering screen. It is a pitiful scene, completely degrading to the quality of life of the overdosed patients.

The second problem is concerned with the food served in the nursing home. While some of the meals were excellent, more frequently the lunches and some of the dinners consisted of starchy foods, such as potato concoctions, spaghetti or macaroni. The terminally-ill, who are mainly in wheel-chairs or are bedridden, require small portions of well-balanced meals and not large portions of starchy food. Moreover, many of the terminally-ill must be fed and the inadequate staff cannot possibly feed the patients in a proper and timely fashion. Much of the food is cold when the patient is fed, with the result that much of the food is not eaten and disposed of as garbage. If it were not for a small coterie of volunteers and family members, the feeding problem would have been even more serious than it is.

For those patients who are ambulatory and can feed themselves, the nursing home may be serving a useful purpose. But for the terminally-ill, home health care under a hospice program would be far more preferable.

After having experienced nursing home care for my wife, I would unquestionably have selected hospice care in my own home were such service available. This preference is further strengthened by my visists to many ALS patients still in their own homes. In almost every instance, home health care, either by family members alone or with the assistance of a hospice care program, is far superior to nursing home care both for the ALS patient as well as the family. I have concluded, on the basis of this experience, that home health care under a hospice program is far better and the costs are usually far less than institutional care, whether nursing home, hospital or other facility.

I would, therefore, urge the early passage of H.R. 5180 which would extend Medicare benefits to include hospice care. Thank you for this opportunity to present this statement.

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STATEMENT OF VIRGINIA S. HUMPHREY, R.N., M.P.H., EXECUTIVE DIRECTOR, CHESHIRE, CONN., PUBLIC HEALTH NURSING SERVICE

Hospice development has continued to be a high priority of mine in each endeavor since leaving the Hospice Institute of the Connecticut Hospice as former Director of Hospice Program Development developing hospice home care around this state so that everyone faced with a terminal illness has the option of choosing hospice as an alternative to the traditional care or lack of adequate care when facing death. I continue to spend evenings as time permits not only with hospice development around the state enabling communities to get a firm grasp on the methodology for planning and implementing their hospice program in the most appropriate and cost-effective manner to meet that community's needs, but also in training staff and volunteers for hospice care. Building a sound fiscal base has been paramount in the methodology so that hospices will continue to thrive after the first zeal of seed money or

grants have been received and utilized in the start-up costs of operation. For without this firm financial foundation, many hospices will not survive; this is of serious concern to many of us working in the hospice movement.

This new hospice legislation (H.R. 5180/S 1958) addresses that concern ensuring all hospice programs who meet the standards of hospice an opportunity for funding through Medicare and at the same time stimulating the private insurance companies to consider incorporation of hospice benefits. This new bill will support fledgling hospices in our state and elsewhere less financially endowed than those few institutional-based modes with demonstration project monies to support them. It will bring added benefits to all hospices for services not currently covered by Medicare, such as homemaker services, respite care, counselling for bereavement and dietary needs among other areas not previously included, and extend reimbursement for nursing and home health aide services, therapies and medical social services.

Who needs this bill? Hospice home care programs and those not benefiting as a HICFA demonstration model, as is Connecticut Hospice. Recent organized opposition to this legislation by the present administrator of Connecticut Hospice must be confusing to you, our own legislators, and leaves credible hospices around the nation with feelings of abandonment by their "mother" organization, just when they thought they were about to achieve financial security. Does not this opposition to the bill appear to be self-serving?

We in Connecticut need to facilitate new legislation to give options in funding for all hospices to choose depending on their individual model. Such legislation is not mandatory for any existing model not needing it (Connecticut Hospice) but would exist for those who choose to apply and need it qualifying with all Hospice standards, providing survival for many! I trust we can continue in the altruistic spirit in which the Connecticut Hospice first was founded and work together to enable all quality hospices to exist financially to serve terminally ill patient/families with this humane approach and without the threat of bankruptcy.

I wholeheartedly support Panetta's proposed legislation for hospice giving my full endorsement to H.R. 5180/S 1958, as it is a sound piece of work promoting viability for all quality hospices to survive to meet the multi-needs of those suffering from terminal illness.

Yours in the name of sound hospice care in Connecticut and elsewhere.

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CLOVER MANOR NURSING FACILITY,
*Auburn, Maine, March 18, 1982.*

Mr. JOHN SALMON,
*Chief Counsel, House Ways and Means Committee,*
*Washington, D.C.*

DEAR MR. SALMON: We understand that a hearing on S-1958 will be held on March 25th. We would appreciate it very much if you would enter the attached comments into the record at this hearing on our behalf.

We would also appreciate being sent a copy of all the comments made at this hearing after they are printed.

Thank you.

Sincerely,

WILLIAM E. GILLIS,
Administrator.

Enclosure.

S-1958 HOSPICE CARE BILL

Members of the House and Ways Committee, my name is William Gillis and I am an Administrator of a 120 bed I.C.F. in the State of Maine.

I have been studying the need for Hospice care in our state for a number of years and have recently constructed an attachment to my nursing home which will house the first inpatient hospice care center in the state of Maine.

I have studied the Bill (S-1958) under consideration and I am highly in favor of its intent and I also support very highly the need for providing Hospice Care Funding under the Medicare Program.

I however would like to raise the following issues for consideration by your committee.

1. In section, (B) (ii) page 7, of this bill it states that "The secretary shall determine a national average medicare per capita expenditure amount." Has any determination been made up to this point in preparation for this legislation on what the national average cost is projected to be?

2. In section (dd) (1) page 9–10, of this bill it states that services will be allowed for inpatient care "as the secretary determines to be appropriate to provide such care." Has any criteria been established up to this point defining appropriate inpatient care? If not: is there some way for use to provide input on this issue?

3. In section (2) (A) (iii), page 11, it states that the individual can only stay 20 percent of his/her days in the hospice program in the inpatient part of that program. We find this section to be overly limiting and lacking in the necessary flexibility to allow a hospice program to take care of an individual in the most appropriate setting for that individual. We would strongly recommend the deletion of this item from S. 1958.

4. In section (D) page 12 it states that a hospice program "does not discontinue the care it provides with respect to a patient because of the inability of the patient to pay for such care." We find the intent of this section to be noble in nature but very impractical to implement. We suggest deletion of this section from the bill.

Thank you for listening to my comments and I hope this committee will act favorably on this legislation.

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COMMUNITY HOME HEALTH AGENCY,
*Longview, Wash., March 22, 1982.*

Hon. ANDY JACOBS, Jr.,
*Chairman, Subcommittee on Health,*
*Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: I would like to take this opportunity to express my support for (H.R. 5180) or (S. 1958), the Hospice Reimbursement Act. I believe that this bill has merit for at least two important reasons:

(1) Hospice makes it possible for the terminally ill to choose dying in familiar surroundings with the support of loved ones.

(2) In these times of severe budgetary constraints, this bill can result in significant monetary savings to taxpayers. Here are five examples from our own caseload, which averages 15 terminally ill persons per month:

| | |
|---|---|
| Last week of life: | |
| 4 nursing visits | $148.00 |
| 1 M.S.W. visit | 49.00 |
| 6 aide visits | 245.00 |
| Total | 297.00 |
| Last month of life: | |
| 9 R.N. visits | 333.00 |
| 5 M.S.W. visits | 162.00 |
| 6 aide visits | 245.00 |
| Total | 740.00 |
| Last month of life: | |
| 8 R.N. visits | 296.00 |
| Last 1½ weeks of life: | |
| 9 R.N. visits | 333.00 |
| 2 M.S.W. visits | 98.00 |
| 2 aide visits | 54.00 |
| Total | 485.00 |
| Last 5 months of life: | |
| 21 N.R. visits | 777.00 |
| 6 M.S.W. visits | 294.00 |
| Total | 1,071.00 |

Versus: Hospital, 7 days at $350/day, costs $2,450.

These patients all had a high component of volunteer time not reflected in the total dollars, to allow them to die at home.

I would request two changes in the bill.

(1) Section 3(A), Section 1814(A), Page 5, Line 8: Should read: "the medical director or the individual's attending physician".

(2) Page 7, Line 7: Do not limit death to cancer.

I look forward with anticipation to the result of the Congressional vote on this important issue.

Sincerely,

LORRAINE A. BERNDT, B.A., C.N.A.,
*Administrator.*

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STATE OF CONNECTICUT,
DEPARTMENT OF HEALTH SERVICES,
*Hartford, Conn., March 22, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means,*
*Washington, D.C.*

DEAR MR. SALMON: As you know, the State of Connecticut was the first state in the nation to draft and implement regulations to govern a hospice. That section, now in effect through the State of Connecticut Public Health Code, is known as Section 19-13-D4b—Short Term Hospital, Special, Hospice. Embodied in the regulations are standards of care, and bereavement components. Any provider in Connecticut wishing to start a comprehensive hospice program of care may apply for this licensure designation. They need not be a free-standing unit.

The Connecticut Hospice applied successfully and as such became the first licensed hospice in the United States and the only one in the State of Connecticut.

The State of Connecticut has been in a leadership role not only with respect to developing hospice standards of care, but also in effecting legislative change, at the state level, for hospice reimbursement. (Exhibit 1, PA 78-76)

We have examined H.R. 5180—S. 1958, Medicare Bill for Hospice Reimbursement now proposed and under scrutiny by your Committee. We admire your vision and leadership. However, the bill as drafted appears to have some inherent problems.

We foresee that under the current terms of this legislation, hospices may proliferate without proper standards for quality assurance and without proper mechanisms for cost containment. Hospice Benefit for Medicare eligible patients.

(1) Substitute a prospectively negotiated, cost-based reimbursement system as the cost control mechanism rather than utilizing the capitation methodology to control spending.

(2) Eliminate the restriction on the percentage of reimbursable inpatient care days available to each individual patient, or change the allowable ratio of home care to inpatient days from 80:20 to 50:50 with an allowance for a higher ratio of inpatient care for patients who reside outside of the area served by hospice home care.

(3) Include quality standards for accreditation which are based on the standards for hospice care now being developed by JCAH. Include a more precise statement of quality standards with separate state licensure regulation as a "hospice", and minimum daily census requirements (combined home care and inpatient count).

(4) Require evidence of non-discriminatory practices in the selection of patients to assure patients are accepted on the basis of medical need without regard to potentially prejudicial factors of life expectancy and source of reimbursement.

Very truly yours,

DENNIS F. KERRIGAN,
*Deputy Commissioner.*

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STATEMENT OF ROSEMARY JOHNSON-HURZELER, ADMINISTRATOR, CONNECTICUT HOSPICE, INC., BRANFORD, CONN.

Chairman Jacobs and distinguished Members of the Committee, I am Rosemary Johnson-Hurzeler, administrator of the Connecticut Hospice, Inc. in Branford, Connecticut. Thank you for the privilege of appearing before you on behalf of the Connecticut Hospice to testify on such an important piece of legislation as the medicare Hospice bill. The committee has demonstrated great leadership, wisdom, courage and vision in addressing the issue of reimbursement for Hospice care.

By our testimony today we hope to support you in your efforts to hasten the arrival of a system through which quality hospice care can be widely available at a cost that does not burden the medicare system.

As the first American Hospice, we have cared for nearly 3,000 patient/families since beginning operations in 1974. We are the first licensed hospice in the United States and the only licensed hospice in the State of Connecticut. Our patient population represents one-half of all terminally ill patients in the geographical area in

which comprehensive hospice home care and inpatient services are available. Approximately 13 percent of all terminally ill patients in the State of Connecticut are cared for either by utilizing our combined home care and inpatient services or by availing themselves of our inpatient facilities which serve the entire State of Connecticut.

In fiscal year 1981, the Connecticut hospice cared for 554 different inpatients for a total of 12,015 inpatient days. The all inclusive per diem charge for Connecticut hospice in patient care is $285.00. This per diem rate embraces the physician component of inpatient hospice care. Therefore, the total cost of caring for these 554 patients at the Connecticut hospice was $3,424,275. The reasons for inpatient hospice admission of a 10-percent random sample of these patients were analyzed. Based on this study, we have concluded that in almost every case, those patients requiring inpatient care would have been hospitalized at local acute care hospitals if the Connecticut hospice inpatient facility were not available.

The average per diem cost at one of the acute care hospitals serving the same area as the Connecticut hospice is approximately $370. The estimated cost of caring for these 554 patients at an area acute care hospital is $4,445,500. Therefore, the savings realized for the Connecticut hospice patients alone is over $1 million, that 74 percent of these patients are medicare eligible—by virtue of their age or disability—the savings to the medicare system in 1 year is $750,000 Futhermore, the Hospice care which these patients received is a higher level and more appropriate form of caring for the terminally ill patient and his/her family than is provided in an acute care general hospital.

In our written report to the committee, we have displayed the distribution of costs experienced by our Connecticut hospice patients. The high concentration of low cost patients exhibited are offset by the percentage of patients with extremely high costs. Thus, the average per patient expense is increased. This distribution is bound to present itself to other hospice care providers.

It is important to appreciate the significance of the statistical configuration of cost distribution in order to arrive at the most appropriate reimbursement methodology for Hospice care. It is of utmost importance that the methodology employed to reimburse hospice providers take this distribution of costs into consideration. Hospices must not be compelled by finacial exigencies, to avoid caring for the high cost patients. This clearly would not be in the patient's interest and would interfere with their needs for the hospice system of care. These patients here represently fully one-third of all patients needing hospice care.

We respectfully suggest the following changes be considered:

(1) Prospectively negotiated, cost based per diem reimbursement with no cap. We have some material that we would be pleased to share with you regarding a model of a system that can be most efficiently implemented in controlling costs and practical in terms of a national application.

(2) Maximum allowable inpatient days may not exceed 50 percent of the aggregate days

(3) Quality assurance should be based on JCAH standards for accreditation. If temporary standards are required, they should be more precisely stated with consideration given to a minimum average daily census (home care and inpatient) and institutional quality standards should be related to separate state licensure as a "hospice."

(4) Evidence of nondiscriminatory practices in the selection of patients by social characteristics and level of illness.

In conclusion, we would like to note that President Reagan has stated, the Connecticut hospice has pioneered the modern hospice movement in this country and has inspired groups in some 800 other communities to follow its trail.

The National Hospice Organization has stated, the Connecticut hospice has the most valid and comprehensive data which is relevant both to hospice programs everwhere and to this legislation.

The State of Connecticut Department of Health Services endorses the position of the Connecticut hospice. This is expressed in their letter to this committee.

Please know that we stand ready to assist you in whatever way we can be most helpful. If it would aid in your deliberations, we would be honored to have you come and see us.

STATEMENT OF HELEN SMITS, M.D., MEMBER, BOARD OF DIRECTORS, CONNECTICUT HOSPICE, INC.; AND FORMER DIRECTOR OF HEALTH STANDARDS AND QUALITY BUREAU, HEALTH CARE FINANCE ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

I am very pleased to have this opportunity to express my views on H.R. 5180/S. 1958 the Medicare Hospice bill. The addition of hospice benefits to existing Medicare coverage will represent an important step forward for many beneficiaries and this committee is to be congratulated in taking the lead for the development of such important legislation.

In your enthusiasm for the hospice concept, however, you should be careful to insure that the new coverage accomplishes the intended goals without escalating costs and without providing inappropriate incentives to hospice organizations.

I would like to confine my comments to problems with the proposed reimbursement mechanism. Other concerns with this bill particularly in the area of quality standards are well covered in the testimony of other representatives of The Connecticut Hospice, Inc.

The presently proposed reimbursement mechanism has several serious flaws. These are:

The bill assumes that Medicare patients with terminal illness are relatively homogeneous group and that those who choose hospice are a representative subset of this group. This is not the case.

The bill invites manipulation of its reimbursement mechanism through patient selection and through timing of the process by which patients select the hospice benefit.

Hospices are and will remain relatively small organizations. Those that accept all patients run the serious risk of being put out of business by the cost incurred by a single high cost patient. Such a system does not allow for rational financial planning.

Although appropriately emphasizing outpatient care the bill does not deal with the problems of a hospice such as ours that offers inpatient services to many individuals from out of the service area of home care.

I would like to illustrate in a somewhat personal manner the meaning of the data presented in the testimony of R. Johnson-Hurzeler, Administrator of The Connecticut Hospice, Inc.

Medicare patients are a very diverse group; the diagnosis of a terminal illness has a different impact to the different members of this group. The premature death of a 66 year old man who has barely begun to enjoy his retirement, is a tragedy to him and his family. The death of his 92 year old father, already resident in a nursing home, is a cause for sadness of a much less acute because much more predictable sort. The first individual and his family may be in great need of hospice services; the second is an inappropriate hospice candidate.

In addition to the natural variation of cost by the great age range of elderly Medicare beneficiaries, we must remember the silent minority: those who are entitled to Medicare because of total and permanent disability or because of end state renal disease. Beneficiaries under the age of 65 now constitute almost nine percent of all those entitled to Medicare.

The needs of these individuals must be considered in any new Medicare legislation, and particularly in any legislation aimed at individuals with terminal illness. These beneficiaries and their families often have limited financial means and have already experienced the stress of caring for a family member with a long term illness. When a terminal illness is diagnosed, they are exactly the kind of families who need hospice but they will often be, as they are in the use of other Medicare services, the most expensive to care for. The wife of a multiple sclerosis victim who already is coping with her household, her children, her dependent husband, and perhaps a part time job, cannot be expected to take on much new care once that husband is diagnosed as having cancer. Any hospice evaluating such a family will know that much support will be needed at home and that inpatient care will be almost inevitable. Yet a well run small hospice, operating comfortably below its cap, may be forced to turn this family away because the potential cost of hospice care which can easily run over $30,000 could "break the bank" for the reimbursement year.

Other forms of reimbursement manipulation exist: a patient like this could be accepted for a while with the understanding that he will reserve his hospice election when his costs get too high. His hospice election could be delayed until his death is imminent. Or the hospice could consciously seek a few patients who would bring down average cost by dying quickly or by using few resources before they die. Nurs-

ing home patients already supported by Medicaid would be ideal for such a reimbursement manipulation.

In conclusion then, we at The Connecticut Hospice, Inc. strongly support the concept of a hospice benefit for Medicare beneficiaries. We believe, however that the proposed reimbursement mechanism is not the best way to provide that benefit. We urge carefully exploration of alternative approaches to reimbursement, such as the use of a prospective rate before this bill becomes law.

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TAYLOR, MICH., *March 24, 1982.*

Mr. JOHN J. SALMON,
*Committee on Ways and Means,*
*House of Representatives,*
*Washington, D.C.*

DEAR MR. SALMON: Enclosed is a list of people who support your bill, H.R. 5180, which permits Medicare reimbursement so that more people can take advantage of the hospice program.

MARY ESTEP, R.N. (And 12 others.)

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GARDEN CITY, MICH., *March 17, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means, House of Representatives, Washington, D.C.*

DEAR MR. SALMON: It has come to my attention that legislaton has been introduced in Congress to provide Medicare reimbursement for hospice programs.

As a physician, I have had the opportunity to deal on many occasions with terminally ill patients. There is no doubt in my mind that the concept of hospice is a very appealing one. Hospice comes to fill a vacuum in between the hospital care, the nursing home care, or the home care. There are many patients that can benefit greatly from this concept.

From the medical standpoint, the patient can be provided with the specialized care that he or she requires, and at the same time be provided with the home atmosphere that is so important and necessary in the last few days of a human being's life. Naturally, this environment can not be provided in the atmosphere of an acute hospital or in the regular nursing home. On many occasions the complicated medical problems of the patient prevent an adequate home care too.

From an economical standpoint, the hospice has to be a much cheaper proposition than the acute hospital and could decrease considerably the length of hospitalization of many patients. Naturally, the need for insurance coverage of these services is unquestionable. Very few people in this country could afford to pay directly for the cost involved in any kind of place, be it called a hospital, hospice, or nursing home. Considering that many of the terminally ill patients are senior citizens, there is no question that the first insurance that should provide coverage for these patients should be Medicare.

In summary, I think that the legislation introduced by Congressman Ford could be a great benefit for all the American population. I realize the difficult times that we are living in from the economical standpoint, but I feel that the care of a terminally ill patient should be of paramount importance to all of us.

Respectfully,

ANGEL FARINA, M.D.

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STATEMENT OF HUGH T. FARLEY, CHAIRMAN, NEW YORK STATE SENATE COMMITTEE ON AGING

Good morning. I am New York State Senator Hugh T. Farley, Chairman of our State Senate Committee on Aging, and Chairman of the National Conference of State Legislators Subcommittee on Aging. I am speaking today in the former capacity, although I wish to convey NCSL's general support of the hospice concept.

New York was one of the first states to implement a formal hospice program, under terms of legislation I sponsored in 1978. Our legislation defines "hospice" as, "a coordinated plan of home and in-patient care which treats the terminally ill patient and family as a unit, employing an interdisciplinary team acting under the direction of an autonomous hospice administration." Hospices must provide palliative and supportive care to meet the special needs arising out of physical, psycho-

logical, spiritual, social, and economic stresses which are experienced during the final stages of illness, and during the dying and bereavement.

New York State is in the third year of a hospice demonstration program which seeks to evaluate the use of hospices in the health care system of the State and to aid in the establishment of permanent regulations governing certification and operation of hospices, including a reimbursement methodology showing cost-benefit. However, when this law was passed, it did not provide funding for the designated hospices. All parties involved knew this, but assumed that an acceptable reimbursement mechanism would eventually be implemented. The Office of Health Systems Management in the State attempted to develop a reimbursement mechanism whereby third-party payors, such as Medicare and Medicaid, would cover hospice services delivered to their beneficiaries. New York State submitted a waiver request to the Health Care Finance Administration to provide Medicare and Medicaid reimbursement for all its demonstration projects, but, unfortunately, the Health Care Finance Administration only approved reimbursement for two of the fifteen New York State projects, the two which were selected to participate in the National Hospice Demonstration Program.

As a result, only these two hospice demonstration projects received full Medicare and Medicaid reimbursement under the federal guidelines. For the remaining thirteen, only specific components of hospice in-patient and home-care service are currently reimbursed by the traditional methodologies. Reimbursement for these covered services follows the methodology currently utilized for the specific type of provider and services.

There is a severe inequity within the present reimbursement structure, as it encourages high utilization of hospital stays and medical procedures in acute care facilities. Conversely, the lack of Medicare reimbursement for hospice care is a disincentive for providers and patients to opt for hospice care. Dying patients do not always require expensive acute care hospitalization, which is the type of care traditionally provided for by our existing system.

It is important to understand that the hospice benefit is not an additional service—it is an alternative, a substitute to institutionalization. Medicare reimbursement will create an incentive for physicans and patients to choose hospice, a less expensive, more appropriate form of care.

Available data indicate that coverage of comprehensive hospice services may be added to Medicare without increasing the cost of the Medicare program. In light of the soaring costs of medical care, this is a more cost-effective way to spend our money.

In New York State, the lack of an established rate of reimbursement specifically for hospice care has created a "piecemeal" approach to delivering hospice care. For example, a hospice program loacted within a hospital receives from Medicare a different rate of reimbursement than a nursing home facility would, both of which should be providing the same level of care to patients with similar needs. This "piecemeal" approach not only imposes hardships on some providers, but it also disguises the true cost of hospice care.

Medicare reimbursement would provide coverage for all of the services which are essential to the concept of comprehensive hospice programs and which are required by the definition of a hospice. As the situation exists right now, there are nonreimbursable items of hospice care, such as bereavement, education, nutritional counseling, pastoral counseling, and pharmaceuticals for pain control which must be paid for entirely through private payment or must be sponsored in full by the provider. Giving Medicare coverage for hospice would bridge this gap and would eliminate the need to base hospice reimbursement on the type of provider rather than the type of service.

We, in New York State, are now approaching the end of our demonstration project, and we are in the process of devising legislation which will implement hospice on a full-scale basis. I am concerned that our programs appropriately parallel federal legislation in order for hospice patients and providers in New York State to take full advantage of cost-effective reimbursement programs.

I have reviewed Congressman Panetta's bill very carefully in order to ensure that our efforts are congruous with his proposal. His proposal to allow Medicare eligible patients to utilize their benefits to obtain services from bona fide hospice programs is a very positive action. I encourage you to keep the language of the proposal as flexible as possible in order to qualify reimbursement for all aspects of the facility-based and the community-based models in the New York State demonstration project. There needs to be room for flexibility, innovation, and local autonomy to assure the development of quality hospice programs.

I take cognizance of the fact that Mr. Panetta's bill ensures that any certified hospice provider may not discontinue hospice care for a patient/family because they run out of benefits. We need this protection to assure a continuity of care in spite of any unforeseen inability to pay.

New York State requires that hospices be certified, and allows actual "hands-on" service to be provided either directly or by contract with an existing health care provider who may be certified to perform certain component services of hospice care, such as a certified Visiting Nurse Association which may provide home care but would not qualify as a certified hospice. Utilizing existing providers on a contractual basis is an arrangement with tremendous cost-saving potential. I encourage clarification of provisions of Congressman Panetta's bill to ensure that components of hospice care may be provided by other forms of health care providers operating under contract to a hospice. This clarification will work hand-in-hand with the determination to leave certification and licensure requirements up to the individual states which already have or might adopt such requirements. I recommend that the language of this legislation remain as flexible as possible in these areas.

As always in health care, I recognize the danger of over-utilization of services. I do not wish to promote unneeded building of hospice facilities, and neither do I wish to expand expensive acute care in-patient hospitalization. But I am concerned that this proposal adequately cover the care provided in our hospital-based hospice facilities. Data from our evaluation may show that hospital-based hospices attract different populations than community-based facilities. Hospital-based hospices may very well attract patients who are more sick or need a longer in-patient stay, or have limited access to primary caregivers, rather than those patients who are more independent, or more geographically mobile. While assuming that hospice care does not result in significant new costs to the Medicare trust fund, I think that there needs to be careful attention in establishing the "cap amount" expenditure limit so that there is enough flexibility for our hospice-based hospices to handle these situations.

Volunteerism, including trained professionals and providers of support service is an integral part of hospice care in New York State. I fully support this component of hospice care and stress the importance of using volunteers as a means to extend services in a cost-containment effort. I strongly recommend that you retain and emphasize that voluntary and private sectors of our communities take the responsibility to raise funds for hospice care over and above the Medicare limitations. We need this sharing and willingness to relieve some of the burden on our public systems.

Hospice is not another form of long-term care. In creating legislation, we need to address the fact that hospice care does not necessarily represent an in-patient facility or a place to go. Hospice represents the responsibility for a plan of care, whether it is in-patient nursing home, or home-health services. The control for this care is what terminally ill patients want and need.

New York stands as an example of a state which has been a leader and is already well into the successful establishment of a hospice program. We have learned a great deal from our three-year demonstration program, and now hope to proceed with the certification of additional hospices. We have accomplished a great deal, but the lack of federal reimbursement has been the greatest single obstacle which we have not been able to overcome. Funding is vital.

In case you are wondering, "why now, what is the urgency?" Why not wait until our State demonstration and the HCFA demonstration are complete and the results of the evaluations are fully formulated? To that, I reply that the jury is in . . . there will always be more to learn—but how much more do we need to know? The benefits of hospice are obvious. It is shown to be a cost-effective form of care. And so, the significant need for a stable and comprehensive reimbursement mechanism is obvious. This has been our single most important lesson. We cannot afford to wait.

I, therefore, urge active consideration of Congressman Panetta's bill, with the recommendation that it be reviewed with an eye toward enhancing the flexbility of the individual states to certify a variety of hospice models within the reimbursement structure.

The widespread support for this bill is evidenced by the grassroots support which I bring to you from my own State, as well as the national endorsement by more than 200 United States Senators and Congressional leaders who are co-sponsors of this piece of legislation.

As I end my message today, I would like to, once again, reiterate my concern for the need for Medicare reimbursemnt for hospice. Without reimbursement, there may very well be no hospice. My good business sense tells me that hospice care is an appropriate, cost-effective form of care; and the caring which goes along with hospice cannot be understated. There are thousands of terminally ill people who could

well benefit from hospice programs if they were available and reimbursable. I, therefore, endorse and support this bill, and I urge prompt action to make the federal government a partner with states such as New York, in providing hospice care. New York State has taken the lead; Congress should, too.

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STATEMENT OF HON. DANTE B. FASCELL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF FLORIDA

Mr. Chairman, I want to thank you for the opportunity to be heard on the important issue of hospice care. I commend you for your initiative on this issue and hope that the information that comes to light during this hearing will help to produce a coordinated, consistent national policy regarding coverage of hospice care and Medicare.

When I decided to join in sponsoring H.R. 5180, a bill to provide for coverage of hospice care under the Medicare program, I was compelled by the evidence of a grass roots movement of compassion that has spread over our nation. Currently, hospice care is offered by more than 200 organizations supported by private groups and individuals. This care, which provides palliative care for terminally ill patients in a home-like environment, has expanded in response to the realization that institutionalized care does not meet the needs of all patients and all illnesses.

The objective of the hospice is to make the patient's remaining days as comfortable and as meaningful as possible and to help the patient's family cope with the stress brought on by such a situation. While the advances of medical research are formidable and must continue to have financial support, we must also face the realities of our limitations and meet the challenge of terminal illnesses with compassion and reason. The hospice movement has realized that traditional methods of caring for the terminally ill are often inappropriate and unduly burdensome, both financially and emotionally.

Of course, the present problem is that hospice care services are not covered by federal programs nor by most private health programs unless the services provided by the hospice fit into one of the categories of traditional care already designated. Therefore, terminally ill patients are usually forced by financial considerations to choose between hospice care and the more expensive, perhaps inappropriate, care of a hospital or other institution.

According to a 1979 GAO report on hospices, the potential population that hospices could service is 400,000 persons per year, based on the number of persons who died from cancer in 1977. Since 60% of these persons were 65 years or older, potential Medicare eligibles who could use hospices would be about 250,000 persons.

However, as the situation stands now, patients being cared for by hospices cannot use their Medicare benefits to obtain hospice services because hospice care per se, is not a covered benefit under the Medicare program. Thus, because of financial reasons, many terminally ill patients are forced to choose institutionalized care. In addition to destroying the financial integrity of many families, this choice also costs the federal government approximately $1.5 billion for terminal care in the absence of an alternative. Moreover, this choice means more than $7,000 in Medicare funds go to provide health services for the average terminally ill cancer victim, just in the last six months of life.

On the other hand, the hospice offers care that is both compassionate and cost-effective. The total cost of hospice care averages out to be $4500 per patient/family. The cost of the average day of care for the terminally ill in a hospice is about one-fifth of the cost of care provided in a typical American hospital.

Therefore since the cost of hospice care is much lower, under the proposals before you, Medicare would save the difference between the cost of hospice care and the cost of hospital care in the last six months of these patients' lives. How much of this savings would be cancelled out by the increase in those eligible for Medicare reimbursements is presently unknown. However, such a change in the law to allow for Medicare reimbursement of hospice services is likely to reduce Medicare expenditures for the terminally ill and, therefore, be a cost-saving measure as well as a compassionate one.

The growing expenditures of entitlement programs have received a great deal of attention of late and deservedly so. In these times of large deficits, a recession, and the need to reduce federal spending, a proposal for reimbursement of hospice care is timely as an effort to reduce expenditures while recognizing the strictures that current policy has placed on the terminally ill seeking appropriate care.

I wish there were more information on just how many people are currently using hospice care, how many more people would become eligible for reimbursement as

compared to the reduction in expenditures for expensive cancer therapy, and how much a proposed change would affect these hospice programs that are often staffed by volunteers. Perhaps these hearings will produce just this sort of information and will provide ways to ensure that the large volunteer effort characterizing present hospices continues and that reasonable, enforceable standards for hospices are established by the federal government or by States.

In H.R. 5180 in particular, provisions for the cap on reimbursements and the election of hospice benefits, thereby waiving entitlement to all the non-hospice benefits under Medicare except for benefits for the attending physician, make this bill both reasonable and humanitarian.

I urge this Subcommittee to take favorable action on the proposal before you and, again, applaud your efforts to examine the issues relating to Medicare coverage of services provided by hospices.

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STATEMENT OF REV. HUGH A. WESTBROOK, PRESIDENT, FLORIDA STATE HOSPICE ORGANIZATION, INC.

Mr. Chairman, my name is Hugh Westbrook. I am President of the Florida State Hospice Organization and Executive Director of Hospice, Inc., a community-based hospice serving Broward, Dade, and Monroe Counties in Florida. I am an ordained United Methodist minister.

I submit this testimony as President of the Florida State Hospice Organization and include for the record, as part of my testimony, the unanimous resolution of support for H.R. 5180 adopted by the Board of Directors of FSHO at its January 29, 1982, meeting. (See attached)

The Florida State Hospice Organization is a voluntary, non-profit association of hospices, physicians, clergy, nurses, state legislators, hospitals, home health agencies, and nursing homes in our state. We are organizationally developed to promote quality hospice care, advance the interests of the terminally ill, and to uphold the Standards of Hospice Programs of Care, as published by the National Hospice Organization.

Our member hospice organizations are: Hospice of Palm Beach County, West Palm Beach, Florida; Hospice of Boca Raton, Boca Raton, Florida; Hospice of Sarasota County, Sarasota, Florida; Hospice, Inc., Miami/Ft. Lauderdale, Florida; Hospice Care, Inc., Seminole, Florida; Hospice of Pensacola, Pensacola, Florida; Hospice of the Good Shepard, Winter Haven, Florida; Methodist Hospice, Jackonsville, Florida; Hospice of St. Francis, Titusville, Florida; Hospice of Central Florida, Orlando, Florida; Hospice of the Big Bend, Tallahassee, Florida.

The board of directors include the following: Stella Monchick, R. N., Chairperson, West Palm Beach, Florida; Rev. Hugh A. Westbrook, President, Miami, Florida; Mary Harrison, MSW, Vice Chairperson, Boca Raton, Florida; Sparky Clark, Treasurer, Seminole, Florida; Rev. Powers McLeod, Pensacola, Florida; Dr. Richard Fifec Daytona Beach, Florida; Dr. Betty Foust, Med. Dir., Blue Cross of Florida, Jacksonville, Florida; Chaplain E. Ronal Mudd, Jacksonville, Florida; Cynthi MacKinnon, Orlando, Florida; Esther Colliflower, R.N., Miami, Florida; Dr. James Mowbray, Secretary, Winter Haven, Florida; Dr. Phyllis Stevenson, President, Florida Division, American Cancer Society, Sarasota, Florida; Dr. Ralph Whelan, Catholic Charities, Archdiocese of Miami; Michael Rosen, Jacksonville, Florida; Dr. Jack MacDonald, Oncologist, Tallahassee, Florida; Ms. Connie Hurd, Sarasota, Florida; Emily Sasko, Titusville, Florida; Donald J. Gaetz, Ft. Lauderdale, Florida.

All of the member hospices of FSHO are non-profit, community-based and were started, originally, by volunteer groups, with the sole exception of Methodist Hospice, which was started by a church-related, non-profit hospital in association with community groups.

Two of Florida's hospices are participants in the HCFA Medicare/Medicaid Hospice Demonstration Project. One is partially reimbursed by third party payors and Medicare due to its hospital base. The remainder of our hospice programs receive no reimbursement from Medicare, but barely survive on a hodge-podge of funding sources including private philanthropy, Older Americans Act funds, local government support, etc. All FSHO hospices have substantial volunteer components and substantial local fund-raising efforts.

Florida has one of the highest cancer mortality rates in the nation. Nearly 25,000 Floridians will die from cancer this year. Based on the documented experience of hospice programs, nationally, and given the estimate of up to 40 percent of terminally ill cancer patients opting for hospice services when those services are available as a comprehensive alternative, nearly 10,000 Floridians will need and want hos-

pice care. This fact, alone, and the age of Florida's population indicate that this state will require and likely develop delivery systems for more hospice care than most any other state—assuming existing government obstacles to hospice development are removed.

In the middle 1970's, as hospice pioneers developed Florida's first programs, they were aware of three major concerns which had to be addressed state-wide if hospice was to properly develop and survive.

First, as a new development and as an alternative to the traditional care system, hospice had to be legally recognized as a health service. Early hospice programs in Florida were challenged by home health agencies as illegally delivering care into patients' homes without first being licensed as home health agencies. Thus, hospices' relationships to existing care systems had to be legally defined by allowing hospice to be separately licensed.

Secondly, Florida is burdened with more than its share of home health agency fraud and abuse scandals. Democratic U.S. Senator Lawton Chiles conducted investigations revealing that too many home health agencies in South Florida spend more Medicare dollars recruiting patients than caring for patients. Republican U.S. Senator Paula Hawkins recently stated in hearings before a Senate committee that, "Unfortunately, Florida has more home health fraud and abuse per square inch than the rest of the nation combined." Grand jury investigations, scams, and scandals in the home health and nursing home industries in our state make Florida a model of how not to do it when it comes to home health services. The abuses of some Florida agencies have unfairly tarred others.

State hospice leaders were acutely aware of the need to protect hospice from such unscrupulous operators who would use hospice as a marketing device to profit directly or indirectly from the dying.

Third, even if these issues could be properly addressed, the critical question of the financial viability of hospice programs of care in an environment on non-reimbursement was impossible over the long-term.

In 1979, despite heavy negative lobbying by the home health industry, the Florida Legislature adopted by unanimous vote the nation's first comprehensive hospice licensure and certificate of need statute. The Florida Hospice Act placed into statute the definitions, principles, and standards of the National Hospice Organization.

The immediate impact of the legislature's action was to raise the ire of some members of the state's home health industry who then filed more than two dozen legal challenges in an attempt to stop the implementation of hospice in Florida. Those challenges were heard through the judicial process, defeated at every point, and finally swept aside as being capricious and without foundation by the Court of Appeals.

Another effect of the Florida Hospice Act was to, at least for awhile, cool the questionable interest of some home health providers who had suddenly invented "hospice" in order to apply for participation in the HCFA Medicare Demonstration Project. With standards of care in place and with hospice as a less attractive financial opportunity, home health ardor cooled.

The law affirmed the hard work and promise of the hospice movement by defining hospice as a comprehensive alternative provider which could use other services on a contractual basis, but which was itself responsible to provide a cost effective more appropriate alternative form of care for the terminally ill patient and family.

This basic affirmation of hospice as an alternative is an important requirement of H.R. 5180. Hospice cannot be permitted to develop as a brokerage-like coordination and referral service which is little more than a marketing device for existing providers of typical acute, cure oriented services. There are two basic reasons for this which hospices have experienced in Florida: cost and accountability, and the nature and quality of the care itself.

Most hospices in Florida do not have any form of direct reimbursement. Therefore, one approach some employ is to use existing hospitals, nursing homes and home health agencies who, "under arrangements" with the hospice, bill for their full costs directly to third-party payers such as Medicare. The central coordinating function then becomes additional cost on top of the other agencies' direct care and administrative costs.

Related to this reimbursement dilemma is that the licensed hospice is legally responsible for the care it provides, but so are the other providers who are more responsible to the groups paying for the care they render, than they are to the hospice. Each of these other providers has its own set of regulations and laws which do not address hospice care in any way. So the impact of unique hospice standards and plans of care is impotent.

This last point relates to the compromise that can take place in the nature and quality of the care itself. One hospice in Florida reports about its arrangement with a home health agency that it is generally positive except when non-routine, care-related decisions must be made. An example was given of a patient being cared for at home by a wife who would leave the house every time an aide or other caregiver from the home health agency made a visit. The wife was requesting more visits so she could be away more often. The assessment of the nursing director of the home health agency was that the wife was "running away from reality and attempting to abandon the patient and her role in his care." The reaction of the home health agency was to force the wife to stay home more by reducing the number of aide visits. The wife's reaction was to call the attending physician and demand that her husband be rehospitalized. The hospice interdisciplinary care team's assessment was that the wife needed more support and some respite so she could continue to care for her husband at home, and that her reactions were a normal part of a terminal care situation. The home health agency refused to alter its care plan management decision. So the hospice reacted by hiring an individual aide and increasing the amount of volunteer support and gave the wife a full four day respite from her home care routine. This rather simple situation emphasizes the necessity of giving the plan of care, decision-making role to the hospice interdisciplinary team whose sole speciality is expert terminal care.

H.R. 5180 must be passed as it is a strong endorsement and mandate of hospice as a substitute and alternative for the terminally ill patient. Without its strong sections deeming hospices to be unique providers who cannot broker care with typical "underarrangements" deals the net effect would be the loss of quality hospice care and greater costs.

The hospice movement in Florida and the state government have done their part to enable hospice to develop within the framework of its uniqueness as an alternative choice for the terminally ill patient, with at least some protection from the unscrupulous who by fraud and abuse would profit from the dying. There are now 15 programs licensed or regulated under Florida's Hospice Law. Another five programs are moving toward being licensed. There programs are overwhelmingly community-based, grassroots efforts.

Unless H.R. 5180 is passed into law allowing people to use their Medicare benefits to obtain payment for hospice care, hospice programs in Florida will, for the most part, cease to exist, or be sucked up into the existing health care industry. In which case, hospice's unique promise as a cost-effective, appropriate alternative for the terminally ill citizens of our State will be lost.

H.R. 5180 must be passed as it is; now.

[Attachment]

(Adopted unanimously by the FSHO Board, January 29, 1982)

RESOLUTION OF THE BOARD OF DIRECTORS OF THE FLORIDA STATE HOSPICE ORGANIZATION

Whereas: The needs of the terminally ill for compassionate, competent care are often unmet within the traditional acute and chronic health delivery system in Florida as well as throughout America; and

Whereas: The hospice concept of care, translated by paid and volunteer caregivers in Florida into effective alternatives for the terminally ill, has been legally recognized and established within our state's health care system by the Florida legislature; and

Whereas: The greatest obstacle to the development and even the survival of the hospice movement in Florida and the nation is the lack of an adequate system of hospice reimbursement; and

Whereas: The current Medicare system encourages, through coverage, the use of high-cost, often inappropriate cure-oriented services and discourages, through lack of coverage, the use of hospice care; and

Whereas: A growing number of Fortune 500 companies, including General Electric and Warner-Lambert, have determined that the substitution of hospice care for the traditional array of covered health services not only results in more appropriate care but less expensive services and have therefore added the hospice benefit for employees, dependents, and retirees; and

Whereas: A growing number of private insurance carriers, including the Equitable, Prudential, Provident Life and Accident Company, Northwestern Mutual, and Travelers, have also determined the fiscal soundness of the hospice alternative and have or will soon offer the hospice benefit to subscribers; and

Whereas: A bipartisan coalition of ranking Senators and Congressmen on the relevant committees of the United States Congress have introduced legislation (H.R. 5180 and S. 1958) which would allow a terminally ill Medicare beneficiary to use his/her benefits to obtain hospice services as an alternative to the array of already-covered Medicare services and thereby provide comprehensive hospice reimbursement for the majority of hospice candidates, nationally, and in Florida; and

Whereas: United States Senator Lawton Chiles and United States Congressman Claude Pepper are principal sponsors of this legislation and primary leaders within the Congress on behalf of hospice reimbursement; and

Whereas: The strong support and active assistance of the Florida congressional delegation is vital to the passage of this legislation, which an independent actuarial study has determined will result in a net savings to the Medicare program.

Now therefore be it resolved that the Florida State Hospice Organization extends profound thanks and deep appreciation to Senator Chiles and Congressman Pepper for their championship of the hospice cause and we respectfully urge the other members of the Florida delegation to join in co-sponsoring the Hospice Reimbursement Act; and, further

We resolve to memorialize the National Hospice Organization to strongly and firmly support the efforts of the National Hospice Education Project to seek passage of this legislation, and we memorialize all Florida hospices and friends of hospice to assist, through active support, the drive for passage of H.R. 5180 and S. 1958.

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GOOD SHEPHERD HOSPICE,
*Winter Haven, Fla., March 29, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means, House of Representatives, Washington, D.C.*

DEAR SIR: Regarding House Resolution 5180 which adds hospices to the Medicare system, we will support the Statement for the Printed Record submitted by Hospice of Northeast Florida, Jacksonville, Florida. This statement best represents the position of Good Shepherd Hospice of Polk County, Inc., at this time.

Sincerely,

CARROLL TEETER, *Administrator.*

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STATEMENT OF VERNON GRAMLING, DIRECTOR, GRADY HOSPICE, GRADY HOSPITAL, ATLANTA, GA.

Mr. Chairman and Members of the Committee, the volunteers and staff of Grady Hospice/Grady Hospital in Atlanta, Georgia, deeply appreciate your allowing us to submit this testimony as part of the written record of your consideration of H.R. 5180 before the Subcommittee on Helath, House Ways and Means Committee.

Grady Hospice is a hospital-based, comprehensive hospice program of care which has completed three full years of inpatient and home care service to the terminally ill and their families in our community. During this period of time we have cared for 242 patient/families.

Our hospice program is designed and operated as an alternative form of care for the terminally ill. Patients elect, based on their informed consent, to choose hospice instead of the typical array of acute care, traditional, cure-oriented services. Our services, both inpatient and home care, are a discreet hospice component of care with identifiable administrative accountability and clinical accountability.

Please find as part of this testimony a cost assessment of hospice patients vs. non-hospice patients. This assessment matches patients by age, sex, diagnosis and date of diagnosis. Utilizing scientifically accepted and useful methods of comparison, we matched 22 hospice patients with 28 non-hospice patients, thus providing 22 direct matches and 6 double-matches. Both hospice and non-hospice patients were Grady patients, thus allowing us total access to records, charts, physician documentation, Medicare bills, and financial information. Both groups of patients were studied from the date of terminal prognosis, as determined by attending physicians. All patients, hospice and non-hospice, incuded in this study died on or before December 15, 1981.

Costs included for both groups are a total of all costs, inpatient and home care, including allocation of administrative and overhead expenses according to accepted Health Care Financing Administration guidelines. Focused out of the non-hospice patient group are Medicare Part B charges by private physicians. Physician costs for the hospice medical director are part of the costs included in those reported for hospice patients. Part B costs for private physicians are, likewise, focused out for hospice patients.

| Comparison | 22 hospice patients | 28 nonhospice patients [1] |
|---|---|---|
| Total cost of all care from date of terminal prognosis. | $72,062 | $156,805. |
| Average cost per patient | $3,275 | $5,600. |
| Net savings to payor | $2,325 savings per patient | |
| Days of inpatient care during last 60 days of life. | 7 days average for those utilizing inpatient care. | 16.45 days average for those using inpatient hospital care. |

[1] 22 match, 6 double match.

Notes.

1. Grady Hospital oncological services tend to be less interventionistic so that reported savings will tend to be conservative, perhaps, in comparison to other hospital-based hospices located in hospitals which have oncology programs.
2. Fewer than half of Grady Hospice patients in this study and in total experience have any inpatient utilization. Of those using the inpatient unit, the average total utilization per patient is 7 days.
3. Three of the hospice patients using inpatient care in this study accounted for one fourth of the total number of days of inpatient care by hospice patients studied.
4. 100 percent of hospice patients stidued were admitted into Grady Hospice from the hospital setting as a direct alternative choice to continuing as hospital patients.

This study selected typical patients with typical diseases for analysis. No attempt was made to discriminate or anti-select on the basis of diagnosis of for any other reason.

## CONCLUSIONS

1. When substituted for traditional hospital care in a hospital which has an active oncology program, hospital-based hospice services as a comprehensive model tend to save dollars for the payor. The average per patient savings tends to be 41.5 percent.
2. The experience of Grady Hospice suggests that inpatient utilization can be reduced with the presence of a 24-hour, 365 day comprehensive hospice program.

## RECOMMENDATIONS TO THE HEALTH SUBCOMMITTEE OF THE WAYS AND MEANS COMMITTEE OF THE HOUSE OF REPRESENTATIVES

We urge you to favorably act on H.R. 5180, in its present form, as an appropriate method of recognizing hospice as al alternative form of care. Our hospital-based experience, complimented by our home care program, indicates that the bill, as written, places appropriate and needed emphasis on home care as the primary form of care. We support and encourage retention of the 80–20 home care-to-inpatient care ratio as reflective of not only our experience but of appropriate utilization. It should be kept in mind that our hospice is in an intensive urban area and that we find little difficulty in meeting an 80–20 requirement. There is a direct correlation between the commitment to and sophistocation of the home care component, on the one hand, and the ability to maintain a home-based as opposed to an inpatient-based program of hospice services.

The notion of simply "loosening" the definitions of hospital care within current Medicare guidelines in order to make continued hospitalization of dying persons economically attractive to inpatient facilities is an ill-disguised method of increasing hospital income at the expense of the Medicare system and the taxpayers. As a hospital committed to hospice care, we would urge the Subcommittee to resist such a notion as being self-serving to its proponents and inappropriate for dying persons and in conflict with their expressed desires.

H.R. 5180 represents what good hospice is and what it should be. The volunteers and staff of the Grady Hospice in Atlanta join with the mainstream of the hospital-based hospices in America to urge enactment of this legislation without delay.

Thank you for allowing us to submit our testimony and the results of our experience.

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HOME HEALTH AGENCY ASSEMBLY OF NEW JERSEY, INC.,
*Princeton, N.J., April 2, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: We support the concept of Medicare reimbursement for hospice care. The pending legislation, S–1958 and HR 5180, are positive steps in provid-

ing this needed reimbursement. We would like to commend you for the bill's strengths, and share with you our concerns.

We agree with the provision of the bill for reimbursement of hospice home care services, as evidenced by the stipulation that "no more than than 20% of its aggregate calendar days of patient care be in an inpatient setting". We believe that the cost savings of hospice care reflect the emphasis of home care, rather than institutional care.

We are also in agreement that the services that will be reimbursed under the bill are appropriately: nursing, therapy, social work, psychological support, home health aide/homemaker, and bereavement visits to family members after the patient's death.

The recommendation in the bill for a separate provider of care is an area of concern. On the one hand, a separate provider number would give the hospice program a mechanism to control the financial reimbursement for services. On the other hand, this could create another layer of administration and accompanying costs in an already complex reimbursement system.

The requirement in the bill of a Medical Director for each program is another area of concern. The cost of implementation of this requirement would not be justified by benefit to the consumer. We suggest that this requirement be optional.

We urge the legislators to study the fiscal implications of this bill based on current data available. We are presently collecting data about our hospice costs and will forward this information to you as it becomes available.

Again, we urge careful legislative development and reiterate strong support of Medicare reimbursement for hospice care.

Sincerely,

WINIFRED S. LIVENGOOD,
*Executive Director.*

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HOME HEALTH AGENCY OF YORK AND YORK COUNTY,
*York, Pa., March 24, 1982.*

John J. Salmon,
*Chief of Counsel, Committee on Ways and Means, U.S. House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: After reading HR 5180, I am writing to express serious concern about the language of this bill which is to provide coverage of hospice care under the medicare program. It is my understanding that the intent of this bill emphasizes the desire for reimbursement in regard to care of the terminally ill person and his family.

A major problem of this bill is that it parallels coverage for hospice care with home health care so closely that agencies will be competing for the patient rather than trying to work together to provide care in a supportive manner. Many certified home health agencies are providing skilled nursing, home health aide, physical therapy, occupational therapy, speech therapy, and medical social services to patients who are in a separate freestanding hospice program. What may occur as a result of granting separate and distinct reimbursement to the hospice programs is that hospices may hire their own employees rather than continue to use the services of existing certified home health agencies. This is a clear duplication of effort. (Page 10 lines 7 through 17). Even now some hospice programs will not relate to certified home health agencies in their area with regard to cooperative patient care.

We believe it is necessary to include in this legislation the factor of using available certified home health agencies rather than giving a license to duplicate the same services.

Another problem that arises is terminally ill patients within certified home health agencies who are not formalized participants in a hospice program. Not all agencies have a "formal" hospice program nor may there be one in the vicinity. What happens to reimbursement for these patients if they are not accepted into a hospice program yet need that type of care? Are they denied the right to "hospice care" reimbursement which in HR 5180 includes in-patient care, homemaker service, nutritional counselling and bereavement visits? If these extra services are also to be included for reimbursement as an expansion of general home health services relating in particular to terminally ill patients, then there is no problem. The tenor of HR 5180 does not seem to consider this major item.

A third consideration that greatly concerns our agency is the indication of (re)certification for hospice services by *both* the medical director and the patient's primary physician. It is understandable why the legislation was written in this

manner. We, however, believe that, in the long run, the language on page 5, lines 3 to 25, would create a disastrous effect on the efforts to keep the primary physician actively involved in the care. Having previously worked with two different and distinct hospice programs, I found that this problem was the most difficult to resolve and needed a great deal of delicacy and understanding in approach.

We are strongly in favor of legislation for the "hospice concept" of care, but believe that HR 5180 needs major modification particularly in relation to the discriminatory aspect between home health agencies and hospices. We do not need further duplication of services—we *do* need effective utilization of current programs and reimbursement for the areas that "fall between the cracks".

Yours very truly,

ETHEL J. MICHAEL,
*Executive Director.*

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STATEMENT OF CHARLOTTE N. SHEDD, R.N., M.N., HOSPICE BUFFALO, INC.

This is to indicate support of the above legislation [H.R. 5180], if certain revisions can be effected.

As a student of the hospice concept of care for the past 18 years, as founder of Hospice Buffalo, and as a past member of the Board of Directors of the National Hospice Organization, I am well aware of the need to incorporate hospice into the health care delivery system as a unique and distinct entity.

Having worked with a hospice which has cared for a total of 250 patients and families without any reimbursement whatsoever, for services rendered, I an aware of the absolute necessity for the establishment of a fair and just reimbursement mechanism, if hospices are to survive.

1. Historically, Hospice developed to care for terminally ill cancer patients and their families, these persons being more frequently than others underserved in the health care system, presenting with well identified unmet needs, and hospice being a concept of care based on scientifically sound theory and practice by which to meet such needs.

It seems unwise to expand this patient population for the first time in a Federal program of fiscal commitment, as H.R. 5180 does by opening the target population to any persons with undefined "terminal illness". Along with other "caps" in the bill, wisdom should dictate putting an upper limit on the percentage of patients with other than malignant disease, to be served by hospices and reimbursed under Medicare. A suggested figure might be a percentage of 5–10 percent of the total census.

2. An adjustment appears to be necessary in the ratio of home care to in-patient census in the current draft of the bill. By referring to the attached statistics, one sees that in a hospice keeping 71 percent of its patients at home through their deaths (a higher rate than some hospices are reporting), nevertheless the 20 percent to 80 percent ratio would be a hardship. Adjustment should be considered to 25–75 or more appropriately to 30–60.

3. In the case of all "limits" or "caps" mandated in H.R. 5180, such limits clearly should apply only to that portion of a hospice census which is Medicare eligible, rather than to patients eligible for other reimbursement sources. The attached data shows that only 53 percent of Hospice Buffalo's census are Medicare-eligible. The other 47 percent should not be subject to similar restrictions or requirements.

4. It seems vital to the protection of the Medicare Trust as well as of the consumer to include in the legislation language limiting reimbursement to hospices holding NHO/JCAH accreditation, with accreditation pending, or indicating intent to submit to accreditation within a specific time frame. A proliferation of "hospice-type", "hospice-like", or pseudo-hospices is sure to follow the availability of Medicare reimbursement.

5. The legislation spells out specifics of a minimum hospice team required, but not in keeping with commonly acceptable standards: twelve volunteers for each professional staff has been recommended by the hospices of longest standing and experience. For the staff required in the bill, there should be 48 volunteers. Hospice Buffalo has recruited 250 volunteers, of whom 220 have been given orientation and training.

We look forward to giving full support to a revised bill, made as sound as it can possibly be made.

BLUE CROSS STUDY ON HOSPICE COST EFFECTIVENESS [1]

A preliminary study of the comparative cost of hospice care, carried out by the Blue Cross of Western New York, Inc.

Comparison of Blue Cross costs for:

Control group of patients dying of malignant disease at Buffalo General Hospital (no Hospice involvement) to Hospice-involved Blue Cross subscribers dying of malignant diesase.

Study considered costs of Blue Cross for six months prior to date of death.

| | |
|---|---|
| Control Group (no hospice involvement): | |
| Average 42 days acute care; Blue Cross cost for 6 months of care | $7,207 |
| Hospice group: | |
| Partial Hospice involvement (late referral), average 23 days acute care prior to Hospice involvement Blue Cross cost for 6 months care | 4,300 |
| Hospice involvement for 6 months—25 patients, average 9 days acute care, Blue Cross cost for 6 months care | 1,620 |
| Total Blue Cross cost for 6 months care ($2,000 home care plus $1,620 acute care) | 3,620 |
| Savings to Blue Cross | 3,587 |

NOTE.—There was no Blue Cross reimbursement for home visits for the above.

At currently reimbursed rates, average cost per patient for home visits—$2,000.

Computed as follows: 1, M.D. assessment visit; 3, M.D. visits; 1, R.N. assessment visit; 18, R.N. visits; 4, S.W. and/or O.T. visits; 3.7, additional disciplines; for a total of 30.7, average number of visits based on average of 67 days; 30.7 visits at $65 per visit = $2,000.

*Hospice Buffalo, Inc.*

| | |
|---|---|
| Total number of patients admitted | 112 |
| Home care only patients | 29 |
| PCU only patients | 53 |
| Combination home care and PCU | 30 |
| Total program patient days | 3,033 |
| Home care patient days (67 percent) | 2,043 |
| PCU patient days (33 percent) | 990 |
| PCU only patient days | 544 |
| Combination patient days (47 admissions) | 446 |
| Average stay in PCU (days) | 9.7 |

71 percent of 1981 census were at home at the time of death.

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STATEMENT OF MARY BYMEL, EXECUTIVE DIRECTOR, HOSPICE CARE OF BROWARD COUNTY, INC.

The future of the Hospice movement in America will, in great measure, be shaped by the passage of the Hospice Medicare Bill. This Bill, if appropriately written, will provide the financial support so desperately needed by existing programs, and will help to encourage the development of new programs in the future. I wholeheartedly support passage of a Medicare reimbursement Bill for Hospice.

However, this Bill in its present form is cumbersome, restrictive and appears costly to administer.

Specifically, my concerns are:

1. This legislation appears to promote one model of Hospice care and is set up to follow that single model. This Bill would prohibit the small, community-based program from qualifying for reimbursement.

2. Discussions with other Hospice programs indicate a great deal of dissatisfaction with this Bill as written.

3. Large, free-standing Hospices appear to be favored by this Bill rather than utilizing existing facilities in the Medical community.

4. The Standards for Hospice Care as set by the National Hospice Organization do not appear to be the basis for the development of this Bill.

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[1] 1981 hospice Buffalo census: 47 percent Blue Cross subscribers; 53 percent other, including medicare, private insurors, HMO, self-pay.

I urge this Committee to gather a diversified group of knowledgeable health professionals and representatives from successful Hospices to carefully study and recommend appropriate revisions to the pending legislation.

Major points which require attention include:

A. The section dealing with short term in-patient care should be re-written to clearly state that arrangements can be made with other licensed in-patient units—thereby allowing contracts with hospitals and nursing homes, rather than just other Hospice programs.

B. The role of the Medical Director must be more flexible in order to assure cooperation of the existing medical community.

C. A determination should be made regarding the percentage of administrative costs which will be added to each Hospice program if they wish to participate in the reimbursement program.

D. The many regulations which are inappropriately included should be deleted.

E. The implications of the "cap" amounts for various regions should be clearly defined.

F. Record-keeping requested of volunteers should be reduced to realistic expectations.

G. Rights for other Medicare medical services while the patient is in the Hospice program should not be jeopardized.

H. A patient's 180-day allotment period should not be forfeited should the patient decide to discontinue service for a period of time. This seems unrealistically harsh and can serve no useful purpose.

I. The present Bill suggests not discontinuing the care to a patient because of inability to pay, yet does not clearly stipulate that all patients will be accepted regardless of ability to pay.

As this Bill now stands, it does not encourage the use of existing facilities or the utilization of existing reimbursement mechanisms. We can only achieve sound fiscal management by the use of these systems.

It is naive to assume that this Bill will save dollars for the Medicare system as it is now written. The administrative costs to each Hospice program, as well as to the Federal system will easily match, and probably surpass existing health care costs.

It is much more appropriate, rather, to recognize that this Bill is being proposed to provide reimbursement for a much more humanistic approach to care for the terminally ill patient. Medicare regulations for Hospice patients should be changed so that services not now covered, i.e., assistance in feeding, dressing or other psychological and supportive services so vital for the care of the patient and family be covered. It would also be important to change Medicare regulations for Hospice patients which now require that patients be homebound, and when extended nursing care be needed the patient be institutionalized.

Many of us in Florida are very concerned that our experiences here with Hospice legislation and regulations not be repeated on a national level. Our experience has been one of over-regulation, the preference of only one model of Hospice care, and the attempt to exclude rather than include Hospice which are diversified in meeting the needs of their community.

I encourage you to revise this legislation so that it will remain flexible and relevant to the development of the Hospice concept in our nation.

## Statement of Hospice Care of the District of Columbia

Hospice Care of the District of Columbia began its operations in 1979, and during the past two and one-half years, 165 patients and nearly 500 of their family members, from throughout the District of Columbia, have been helped and cared for through the program.

All of our care is provided in the patient's home. In Washington, families faced with the impending death of a loved one, can turn to Hospice Care for compassionate and practical help. Hospice Care of the District of Cloumbia:

Enables the patient to stay at home with those he loves.

Relieves the burden of pain and anxiety.

Encourages a normal and active a life for the patient as possible.

Helps the family to ease their sorrow with tasks of devotion and care.

Brings professional help into the home, as needed, 24 hours a day.

Provides bereavement counseling for family members for one year if requested.

Diminishes the cost of the illness but not the quality of care.

Hospice Care of the District of Columbia recommends enactment of H.R. 5180 for several reasons. First, and most important, the bill reflects a definition of hospice

care with which we agree. Hospice care should primarily be provided in the home, with inpatient admissions used as backup only. This bill would mandate that 80 percent of the aggregate days of care provided by a hospice program to Medicare beneficiaries be provided in the home.

Second, as citizens of the Nation's Capital, we are acutely aware of the prevailing political climate in this federal city. We understand that a bill which adds net costs to the Medicare Trust Fund would not secure significant support in the Congress. This bill requires that the cost-effectiveness of hospice be realized.

Third, as a home-care-only program, we would not qualify for provider status under this bill without changing our method of operation to include inpatient care. Nevertheless, we believe that the requirement that a provider offer comprehensive hospice services is a good one. It will remove the frustrating necessity of shuttling a patient back and forth between providers. We have already begun to explore various means of providing the requisite inpatient capability, and we are confident that this can be done by contracting with existing providers in this community.

Finally, we would respectfully urge that passage of this law not be postponed. This Congress has a responsibility to the citizens of this Nation to legislate responsibly but compassionately. H.R. 5180 may be unique in the opportunity it provides to the Members of this Congress to exercise their compassion in a fiscally responsible way.

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MARCH 18, 1982.

JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: By unanimous vote of all present, the Hospice Council of Connecticut agreed to support the proposed legislation H.R. 5180 and S. 1958 with the following changes:

1. Prospectively negotiated, cost based per diem reimbursement with no cap.
2. The yearly aggregate mix of hospice home care days and hospice inpatient days should be at a ratio of 50-50. Some allowances could be made to the inpatient care of out of state residents.

The Hospice Council of Connecticut is an organization uniting nineteen active and planned hospices within Connecticut addressing current and mutual goals and problems in the delivery of interdisciplinary services for the terminally ill patients and their families. Our membership includes licensed home health agencies, licensed hospitals, and a licensed hospice as well as other developing hospice programs.

Our cumulative experience and expertise is impressive.

We feel that H.R. 5180 and S. 1958 with the above stated changes will allow us in Connecticut—as well as those other hospices coast to coast—to continue to expand the availability of hospice services at appropriate levels and in appropriate settings to every Medicare eligible hospice patient/family.

Very truly yours,

*Hospice Council of Connecticut.*

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HOSPICE FEDERATION OF MASS., INC.,
*Waban, Mass., March 25, 1982.*

Mr. JOHN SALMON,
*Chief counsel, Ways and Means Committee, House of Representatives, Washington, D.C.*

DEAR SIR: I am writing to you in documentation of the support for H.R. 5180 from hospice providers within the New England area. As the President of the Hospice Federation of Mass., Inc., a consortium of 35 hospice providers in Massachusetts, and as the regional coordinator for information regarding the progress of the NHEP (National Hospice Education Project), I have been in constant contact with hospice providers throughout New England.

At the present time, there are approximately 110 hospice providers within the six New England states of Maine, New Hampshire, Vermont, Massachusetts, Connecticut and Rhode Island. These groups represent community-based, hospital-based, home health agency-based and all voluntary groups and are serving in excess of 200 communities. The legislation has been reviewed in detail by the hospice state organizations in Massachusetts, Connecticut, New Hampshire and Vermont and formal documentation of the results of these reviews is contained below. The legislation has

also been reviewed by individual programs in Rhode Island and Maine, also documented below.

The support for H.R. 5180 in New England is strong and broad-based. It is universally recognized that the existing reimbursement system:

1. Does not sufficiently cover hospice services
2. Skews the delivery of existing services towards the more costly and technological forms of care (such as acute care hospitalization) via its lack of reimbursement for home care
3. Hampers the long term financial viability of hospice and is placing at significant risk those programs already providing quality hospice care
4. Places disproportionate financial responsibility on local communities
5. Denies the terminally ill consumer the option to choose a more qualitative and cost effective mode of intervention in his/her care

The rapid growth of the hospice movement, both in New England and nationally, speaks both to the clinical need for hospice services as well as local community interest in developing services, despite pressured economic times and clear financial disincentives. In a time of spiraling health care costs and increasing fragmentation of the health care service delivery system, the hospice model, with its commitment to centralized case management (in both home and inpatient settings), personalized care and centralized accountability (both in terms of patient care and fiscally) offers a unique opportunity to effectively meet patient/family needs in a far more qualitative and cost effective manner than heretofore available through the conventional care system.

At the heart of the hospice movement is the role of the volunteer as an integral member of the hospice interdisciplinary team. H.R. 5180 preserves the integrity of this role and insures that this unique aspect of hospice care will remain fundamental in service implementation and will insure ongoing maximization of community resources.

Below is a summary of the New England position, by state, on the proposed legislation as defined in H.R. 5180:

*Massachusetts.*—On Wednesday, March 17, 1982, the Hospice Federation of Mass., Inc., a consortium of 35 hospice providers in Mass., voted unanimously to support H.R. 5180 as written. It was universally acknowledged that the failure of passage of this bill, the first to offer more broad based hospice benefits to Medicare recipients, would adversely affect the delivery of hospice care in Massachusetts, both in the development of programs to meet currently unserved areas of Massachusetts, as well as in the threatened shutdown of some key hospice providers. The latter would be particularly painful as the existing providers play key roles in helping new and less developed hospices to implement programs, provide care consultation and provide ongoing consultation and support. Many of the well-established programs are caring for more than 30% of the cancer deaths in their cachement areas, despite financial constraints. This level of care, and the increasing demands for service, cannot be maintained solely via the financial whims of private philanthropy. Failure of these programs will unquestionably result in the return of these patients to the more costly inpatient hospital settings.

*New Hampshire.*—The Hospice Affiliates of New Hampshire, Inc., a consortium of 21 hospice providers in New Hampshire, voted unanimously a formal resolution in support of H.R. 5180 and have so notified their state Congressmen, urging support. Approximately one quarter of the existing hospice providers will be pursuing reimbursement, should a bill be passed. The remaining programs will continue to provide the volunteer component of hospice care as a community resource. The need for both comprehensive hospice care as well as additional patient/family emotional support is recognized and no conflict between the two is perceived. Failure of this bill to pass will not only jeopardize existing providers' ability to provide comprehensive services but will prevent developing programs for attaining comprehensive service capability.

*Vermont.*—The Hospice Council of Vermont, Inc., a consortium of 21 programs, voted unanimous support of H.R. 5180 (21 programs represented). Blue Cross is initiating more broad-based hospice demonstrations in both New Hampshire and Vermont and it is strongly felt that it will be impossible to provide this kind of comprehensive care to Medicare recipients without more broad-based reimbursement for home care. All voluntary programs are also supporting the bill, though many do not intend to pursue reimbursement.

*Connecticut.*—The Hospice Council of Connecticut, representing 19 programs, voted unanimously to support H.R. 5180 with the following 2 amendments:

a. Prospectively negotiated cost-based per diem reimbursement with no cap.

b. Yearly aggregate mix of hospice home care days and inpatient days should be at a ratio of 50–50. In addition, some allowances should be made to the inpatient care of out-of-state residents who might seek care at a regional facility.

Two other amendments were proposed and defeated.

*Maine.*—Contact was made with Cushman Anthony, Chairperson of the Maine Hospice Coalition. At the present time there are approximately 15–20 hospice programs in Maine, the majority volunteer-based. The coalition has not taken a formal position on H.R. 5180 though it has been reviewed by numerous individual programs. The general feeling seems to be that there is a quandary between the recognized need to expand services, but fears that smaller programs and the grass roots quality of the hospice movement will be shut out if the system becomes more formalized. Many programs would not be pursuing reimbursement but have chosen essentially to abstain from a formal position on the bill at this time.

*Rhode Island.*—There is no currently existing state hospice organization in Rhode Island. Contact was made with Bob Canny, Executive Director of Hospice Care of Rhode Island, the principal provider of hospice services in the state (there are some developing groups). Hospice Care of Rhode Island supports H.R. 5180. In addition, Bob Canny is the Region I (Northatlantic) representative to the National Hospice Organization, which voted at its annual meeting in November, 1981, its strong support of this bill. NHO support has been subsequently confirmed via an NHO Board vote and strong positions by its President, Dr. Ed Olson.

From the above summaries, it is clear that there is overwhelming support for H.R. 5180 in New England. Failure of this bill will result in long delays in obtaining needed and appropriate reimbursement for hospice care. These delays will be at the expense of many hospice patients and their families, who will be denied access to hospice services because of the failure of hospice programs to survive without adequate reimbursement. The results of this failure will be too costly, not only in terms of human suffering, but in the inappropriate allocation of health care dollars towards more expensive intervention in the existing care system. I strongly urge the members of the Health Subcommittee to lend their support to the passage of this bill. A unique opportunity, to deal more qualitatively and cost effectively with the needs of a significant medical population, is before us. Let us not let this opportunity pass.

Yours sincerely,

LINDA H. KILBURN, MSW,
*President.*

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HOSPICE, INC.,
*Miami, Fla.*

Re Hearing on H.R. 5180, a proposal to provide coverage of hospice care under the Medicare program

Mr. JOHN J. SALMON,
*Chief Counsel, Subcommittee on Health, Committee on Ways and Means, House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: I am testifying in support of H.R. 5180 as written. I am particularly in favor of those portions of the bill which specify that programs which seek to qualify for hospice reimbursement must have a physician who actively participates in patient care decisions as a member of an interdiciplinary team which is available to provide care on a 24-hour-a-day 7-day-a-week basis. Such programs should have administrative authority over both inpatient and home care service programs as well as provide bereavement care.

I am board certified in Internal Medicine and Medical Oncology. My academic oncology experience included participating in a bone marrow transplant program. While in the Armed Forces I was responsible for starting a medical oncology service in an Army teaching hospital. While in the community practice of medical oncology, I participated in the establishment of a medical oncology ward in a community hospital. I have been involved with the practice of palliative care since 1976. I have been a full-time hospice physician since 1980. During this time I have been associated with three different hospice programs. Each had a different starting point for its staff development; each had a different financial base; all strove to create the kind of program described in H.R. 5180). All had, and continue to have, difficulties in achieving that goal because of inappropriate licensure and accreditation, plus reimbursement schema in our country. From the first I have felt strongly committed to, and have been an active participant in the growth and development of a National Hospice Organization (NHO). I was one of the Founding Directors when the NHO

was incorporated in 1978, and remained on the Board of Directors for two elected terms until 1981. I was Board liaison of the Standards and Accreditation Committee (SAC) of the NHO during the time that committee was analyzing the common characteristics of successful pioneering programs in England, Canada, and the United States and comparing those characteristics to health care programs in the United States. I am immediate past president of the NHO.

The NHO "Standards of a Hospice Program of Care," accepted by the Board and membership of the NHO in 1979, were the result of the work of the SAC. Those characteristics of a hospice program identified in H.R. 5180 (which I summarized in the first paragraph of this testimony) are precisely those program characteristics which SAC found made a hospice program unique. Having those characteristics (which went beyond traditional concepts of health care disciplines and health care programs) enabled pioneering hospice programs to provide a highly competent, comprehensive program of total care which really enabled dying patients to remain at home and comfortable with their families up to and through the time of death. It has been recognized throughout the world, and particularly in the United States, that this kind of achievement was, and is, beyond the capabilities of our current health care service system (composed as it is of doctors in their offices, hospitals, nursing homes, home health agencies, and sitter services). The reason why hospice care is not readily available in the United States is because those very program and care characteristics which enable hospice programs to provide total care for the terminally ill in a home setting are not deemed appropriate and/or significant in our current health care system. The unremitting emphasis in the past 40–50 years on disease therapies by professionals in institutions with cure and/or self-sufficiency as the required end point has left us as a people, as health care professionals, and as health care institutions and programs woefully inadequate and inappropriate in our concepts and our actions when treating patients whom we know will not get better, no matter how vigorously we treat their diseases and follow our organizational guidelines. The needs of such patients are for skilled care that provides comfort and relief even when cure is accepted as an impossibility.

Hospice care is much more than just meaning well. Hospice programs have to do well if they are to live up to their promise of total care for the terminally ill and their families. It is well to remember that hospice patients are not clinically stable. It is well to remember that hospice patients are expected to get worse and die. It is well to remember that being at home with a dying person can be an overwhelmingly fearful experience for both patients and families who may never have faced a serious illness before in their lives, and may well have given little thought to the fact that death would come to them someday. It is well to remember that dying is seldom an all or none phenomenon; rather, when dying of chronic degenerative diseases, it is usually a slowly growing crescendo of physical as well as emotional distress. Programs which presume to lay claim to the ability to be able to help patients and families deal with these facts had best be prepared to deal competently with them, and money set aside for such care will not be well spent unless conditions are made (such as H.R. 5180 provides for) that programs calling themselves Hospice do, in fact, have the capability to deliver truly competent and comprehensive palliative care.

Attached is a summary of the clinical presentation of a patient recently referred to our program. Neither the hospital staff nor the patient's primary physician were able to adequately control the patient's pain. Aside from his disease, this pain was aggravated because the patient wanted to be home and did not want "technical" care, i.e., intravenous, shots, etc.

Both the patient and family and primary physician were well aware that hospice was a home-based program of care which would help patient and family care for themselves while providing the skilled professional and personal support services necessary to enable such care to be effective. They agreed they desired and would work with hospice (see attached consent forms).

Presenting problems were back pain (due to tumor), hallucinations (due to inappropriate doses of mood modifiers), sore mouth (due to poor mouth care and poor eating secondary to loss of appetite and inappropriate feeding techniques), constipation (due to narcotics, poor appetite, weakness, and staying in bed), and a disrupted family ("we don't know what we can do to help but we want him home with us"). Careful and skilled assessment by the hospice RN and MD was done to sort out the curable disorders, identify the mechanisms of symptom generation secondary to incurable disorders, and assess the role of current medications in contributing to or easing the patient's overall distress. The medication regimen was then revised to control rather than react to chronic symptoms; this included educating patient,

family, and primary physician in the principles and practice of chronic symptom control, especially pain.

During the fifty days this patient survived, thirty-nine home visits were made by five different disciplines on the Patient/family Care Team (P/f CT). Nonetheless, the entire P/f CT met weekly to review the patient's and family's situation so that continuity of service could be provided during on-call times, so internal consultation service could take place ("role blurring") and so expand the capabilities and perceptions of those doing hands-on care, and coordination of the hospice program as a whole with other community agencies such as oxygen supply and the American Cancer Society for equipment.

Hallucinations cleared. Pain became controlled (though it needed to be watched closely because increasing doses of analgesia were needed due to spread of tumor). Sore mouth and constipation resolved. Family continued to need much education, counseling and support.

Partly this was due to the fact the family had always been excitable and divided; partly this was because new care problems developed. Reactive depression on the part of patient and family as they had to revise (with hospice assistance) their hopes from cure to comfort, from long term survival to a successful day, etc. Progressive weakness required steady revision of family and program expectations regarding activity and self-care. Shortness of breath secondary to weakness as well as tumor spread into lungs required further symptom control measures. Flatus required counseling for patient's embarrassment, diet changes and room rearrangements.

It should be apparent such care (which is by no means atypical) requires a multitude of persons and disciplines covering a spectrum of needs. It is far from custodial care, but an extremely dynamic situation involving a complex socity of care givers and care receivers continually adjusting and responding to a changing clinical condition. It is not a soft option in heatlh care. It cannot be a sheltered workshop for care givers or care programs. It needs first and foremost to be competent and capable and comprehensive if it is to be at all credible.

It was said as part of a grand jury investigation into nursing home care in Dade County in 1978 that we, the healthy and the care givers, need to be conscientious in speaking up for the real care needs of the dying, for they do not have the time or the energy or the finances to speak up for themselves. Yet, as Senator Hatfield observed in his book, Between a Rock and a Hard Place, the first rule of a bureaucracy is to preserve itself—and this is as true for medical bureaucracy as any others. As a physician, I can sympathize with the feelings of defensiveness, anger, frustration aroused when a physician, a hospital, a home health agency, etc., is told, in effect, that all their training and personal commitment and sacrifice and effort is beside the point in meeting the needs of such patients. If that is the best we can do, then empathetic commiseration is appropriate. But, though I can understand such defensiveness, I cannot tolerate it as an excuse for not providing for the establishment and survival of a program of care which has demonstrated and been recognized as being a true alternative in the communities they serve. All that hinders us is the status quo and H.R. 5180 is a big step forward in changing that.

Attached are a few of the letters sent to the hospice programs I have been associated with over the past six years from families, physicians, nurses, social workers, home health agency directors, hospital administrators, medical societies, corporations, etc., acknowledging that these hospice programs filled a gap in our health care system. H.R. 5180 in my view does a commendable job of defining hospice programs which have the capability of meeting patient/family needs, and safeguarding public monies so that the establishment of a true alternative in caregiving is encouraged.

I urge its passage as is.

Sincerely,

DANIEL C. HADLOCK, M.D.,
*Medical Director.*

HOSPICE, INC. 3485 N.W. 30 St., Lauderdale Lakes, Fl 33311 (305) 486-4085
111 N.W. 10 Ave., Miami, Fl 33128 (305) 325-0245

PHYSICIAN: _____ PATIENT NAME: _____

ADDRESS : _____ DATE OF REFERRAL: __/__/__

_____

The Hospice program of care is designed to be an extension of the primary physician.

I give my consent for the above-named patient to be admitted to the Hospice program of care based upon my diagnosis that this patient is suffering from a life-limiting condition with the life-expectency measured in weeks or months.

I understand that the Hospice program is palliative, not curative, in its goals and techniques, focusing on the alleviation of pain and other symptoms and not employing medical-surgical heroic measures or artificial life support systems; and the patient and family are the unit of care.

I request that the Hospice physician work with me in the care of my patient. I understand that the Hospice physician gives medical direction to the Hospice patient care team (nurses, social services, volunteers, clergy), that he is available as a consultant to the attending physician, and, as indicated by the Hospice Plan of Care, that he provides direct symptom control services to the patient including inpatient, outpatient, and home care visits. I request that the Hospice physician see my patient in order to appropriately develop the Plan of Care and give medical direction to the team.

I understand that I will be consulted about the Hospice Plan of Care for this patient, that I will be welcome at all team conferences concerning this patient, and that progress summaries will be forwarded to me on a regular basis.

I understand that admission to the Hospice program is dependent upon the informed consent of the patient/family and upon their meeting the admission criteria of the Hospice program.

I understand that Hospice services are primarily desiged to be delivered in patients' own homes; and that institutional care is used for short stays primarily for intensive symptom control and directed toward assisting the patient/family to be strong enough physically and emotionally to be cared for at home, if at all possible. Hospice physician services are available on a consultative basis when the patient is in the hospital upon your written request on the hospital record.

Please indicate the extent to which you would like the Hospice physicians to be involved in the direct care of this patient: (choose 1)

☐ The Hospice physician may write any medication or treatment orders and arrange for medical supplies or paramedical services at his/her discretion.

☐ I wish to be contacted directly should the need arise for a change in or addition to current care. However, if I am not immediately available, the Hospice physician may write initial orders, subject to my later confirmation.

Please indicate your preference regarding death certification should this patient die at home: (choose 1)

☐ I will sign the death certificate.

☐ The Hospice physician may sign the death certificate.

Please sign and return the white copy in the enclosed, self-addressed envelope. The yellow copy is for your records.

_____ _____

Physician's Signature Date of Signature

BEST COPY AVAILABLE

# HOSPICE, INC.

## PATIENT/FAMILY INFORMED CONSENT

WE, THE PATIENT AND FAMILY, REQUEST ADMISSION TO THE HOSPICE PROGRAM OF CARE AND WE ACKNOWLEDGE, CONSENT, AND AGREE TO THE FOLLOWING:

We understand the Hospice program as being palliative, not curative, in its goals and techniques; that the program emphasizes the alleviation of physical symptoms including pain, and the identification and meeting of emotional and spiritual needs which the patient and family may experience related to an illness or condition of a life-limiting expectancy measured in weeks or months.

We understand the Hospice program as being primarily services delivered in the home by a team of Hospice professionals and volunteers. These services are available both on a scheduled basis and as needed twenty-four hours a day, seven days a week.

We understand that the Hospice team is not intended to take the place of the family, but rather to support the family in caring for the patient. We understand that the Hospice Medical Director is not intended to take the place of the attending physician, but rather to provide consultation and direct symptom control services as requested by the attending physician.

As the patient, I ask that my family member(s) or significant other(s) respect my choice of Hospice care and, insofar as they are able, that they fulfill the role of primary care giver for me.

As the family member(s) or significant other(s) I/we understand the role of primary care giver and, insofar as I/we are able, pledge to undertake that role with the training and support of the Hospice team.

We give consent and approval for notations to be made on Hospice records and care plans concerning the medical, nursing, psychosocial, religious and personal information necessary for the Hospice to fulfill its functions. We understand that we have the opportunity to join the Hospice team in making the decisions about the variety, frequency, and intensity of the services and techniques the Hospice team will use to help us. We understand that we have access to the Hospice Plan of Care, which details those services and techniques with changes noted on a weekly basis. We understand that we are invited to attend Hospice Team Conferences on a weekly basis to hear and participate in discussions about the services and techniques being used to assist us.

We give consent and approval for the release of information and appropriate medical records to or from any skilled facility, hospital, home health agency, health organization or private physician.

The approximate cost and reimbursement of Hospice care has been explained to us. We understand that we will be charged for Hospice services based upon our ability to pay; that we have been given an opportunity to discuss our financial needs and situation with a representative of Hospice Inc. to the extent we wish; that the decision to accept us into the Hospice program of care will not be based solely upon our ability or inability to pay; and that services of the Hospice will neither be withheld nor curtailed based solely upon any change in our ability or inability to pay.

WE ACKNOWLEDGE THAT WE HAVE BEEN GIVEN AMPLE OPPORTUNITY TO ASK ANY AND ALL QUESTIONS WE HAVE CONCERNING THE HOSPICE PROGRAM OF CARE.

_____
Patient

Date: _____

Witness:

_____

~~Person identified by the patient~~ as being family or significant other or who is the legally responsible person for this patient.

_____

_____

_____

white copy - Hospice, Inc.
yellow " - Patient
pink " - Primary care giver
gold " - Billing

1/81

HOSPICE, INC. 111 N.W. 10 Ave., Miami, Fla. 33128 • (305) 325-0245
3485 N.W. 30 St., Lauderdale Lakes, Fla. 33311 • (305) 486-4065

## HOSPICE PRINCIPLES OF CHRONIC PAIN MANAGEMENT

*(For Health Care Professionals)*

All of us have experienced pain of rather sudden onset and limited duration, such as a headache. This acute pain is often relieved by taking medication intermittently, as needed. However, the pain experienced by many patients with incurable diseases is different in that it is long lasting and often continuous. It is more in the nature of situation than an event. *Chronic pain* of this nature is often accompanied by other symptoms, such as fear and/or anxiety, depression and insomnia.

In treating such chronic pain the principles of treatment, the medications used and the method of administration differ from those used in acute pain. This summary is to help patients, families and professionals to understand the Hospice concept of chronic pain control.

The ten commandments of chronic pain control are as follows:

1) Accurate diagnosis. If the pain is due to a treatable problem, e.g., toothache, hemorrhoids, etc., instead of incurable disease, then treat accordingly.
2) Use simple, i.e., non-narcotic, pain mediations first.
3) Use narcotics when no. 2 fails.
4) Give medications in adequate amounts to achieve pain relief. Recurrent pain resulting from doses too small or administered too far apart usually leads to dissatisfaction with the medication and/or stepwise elevation of drug dose, often without freedom from pain and with confusion and disorientation.
5) PRN ("as needed") is a dirty word in the treatment of chronic pain due to incurable disease. Medications should be given "every _____ hours" depending on the duration of action of the chosen pain medication. The goal is to maintain a constant level of pain control by using the medications to *prevent* pain, which can otherwise be expected to be present, rather than wait for it to recur before reacting to it. *Chronic pain requires chronic medication.*
6) Listen to the patient.
7) Support the family. Given understanding, the family may administer the medication.
8) Use other methods of treatment where appropriate, e.g., nerve blocks, radiation therapy for bony pain, splints, diversional therapy, training in body mechanics, etc.
9) Ask for your colleague's advice.
10) Maintain an attitude of quiet confidence and continuous optimism.

The *total pain* of those ill from incurable diseases includes physical, mental, financial, interpersonal and spiritual dimensions. Real pain is greatly increased by depersonalization during illness. Such real pain may be markedly reduced by helping in areas other than physical pain, and all these areas should be addressed as part of the total program of complete care.

Nevertheless, excellent pain control requires good medical care provided by a health care team skilled in clinical pharmacology.

The aims of *pain control* with medications, with or without narcotics, are the following:

1) identify the cause.
2) prevent pain.
3) erase the pain memory. Since the patient may have suffered months to years of pain prior to Hospice therapy, the memory of such pain may actually cause its recurrence.
4) keep the paitent alert and mentally clear.
5) accomplish a normal affect; the purpose is not to give a "high" nor a "knock-out" of any sort.
6) utilize the most easy route of administration. By far, this route is most often *by mouth* as this allows for patient independence. Suppositories are the second avenue of choice.
7) prevent side effects. Try not to swap one symptom for another.

Domingo Gomez, M.D.
Medical Director

Daniel C. Hadlock, M.D., M.S., F.A.C.P.
Deputy Medical Director
Director of Professional Education

Evelyn Serno, Pharm. D.
Consultant Pharmacist

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## HOSPICE PRACTICE OF CHRONIC PAIN MANAGEMENT

*(For Patients and Families)*

In the past ten to fifteen years, both British and American medical researchers have found that the essential characteristic of effective medical control of chronic pain is the *ROUTINE* ADMINISTRATION of an appropriate pain killer or analgesic. The correct selection of an appropriate analgesic is determined by the nature and severity of the pain, e.g., mild pain - aspirin or Tylenol; moderate pain - codeine; severe pain - narcotics, usually morphine. The correct time interval between doses is determined by the characteristics of the analgesic selected and how it is given, i.e., by mouth, suppository or, rarely, by injection. *THE DOSE USED IS THE DOSE WHICH PROVIDES PAIN RELIEF WITHOUT CAUSING SEDATION.*

The goal of such a program is to *prevent* the recurrence of pain and to *maintain* continuous pain control. It may take several days or even longer to achieve the right body level of analgesic which will make this goal a reality. Drug doses are usually changed no more often than every other day in order to allow achievement of a body level of analgesic at one dose before deciding a different level is needed. No changes in schedule or medications should be made without notifying Hospice first.

Generally, more than one medication is needed to achieve pain control and to avoid side effects. The common side effects of narcotic medications are sedation, constipation and nausea.

1. Sedation — is usually temporary, lasting 48 to 72 hours. Should it persist or occur later in therapy, the dosage can be reduced accordingly.

2. Constipation — a universal side effect of narcotics which can be offset by
   a) prune juice
   b) bran cereal, bran powder
   c) surface acting stool softeners combined with mild bowel stimulents such as Doxidan, PeriColace, & Dialose Plus.

   Sometimes, in addition to such preventative measures, a stronger bowel stimulant such as Milk of Magnesia by mouth or a Dulcolax suppository, should be taken every other day if there is no bowel movement during the interval to prevent impaction.

3. Nausea — a common but not inevitable side effect of narcotics. Anti-nausea medications such as phenothiazines (e.g. Compazine, Thorazine, Torecan, Haldol) are often given with narcotic analgesics for the following reasons:
   a) sedating and tranquilizing properties
   b) increase the pain killing effect of the narcotic
   c) relieve nausea and vomiting.

Other medications may be used in addition to the *basic program of pain killer, stool softener and anti-nauseant.* Exactly what medications may be used depend on what the nature and causes for pain are. When extra medications are used, the Hospice physician will explain the reasons for them, how to take them, and the results and side effects expected.

*"Hospice Care Information Series" No. 1*

Sometimes *other techniques* of pain control such as limited radiation therapy, nerve blocks, skin stimulators, physical and occupational therapy, etc., are valuable assists in helping achieve the ideal of good pain control in the simplest way possible with the fewest side effects. When such techniques are indicated, the Hospice physician will explain the reasons why, how these therapies are used, and what results and side effects can be expected.

The control of chronic pain generally requires more than one medication, more than one technique. Hospice staff is on call at all times and will monitor the administration and effectiveness of any chronic pain control program. *NO CHANGE IN ANY MEDICATION DOSE OR SCHEDULE SHOULD BE MADE WITHOUT INFORMING THE HOSPICE STAFF FIRST.*

In order to best achieve relief of pain and control of symptoms, it is helpful to keep careful records of the doses of medication given, when they are given and the "comfort index." Please mark the number of cc's of solution or the number of tablets given and the time in a bed side chart. Record your impression of comfort control on a scale of 0 to 10 (0 = most comfortable, no pain; 10 = greatest discomfort) for each individual site of pain. Hospice staff will review this chart with you at each visit.

Domingo Gomez, M.D.
Medical Director

Daniel C. Hadlock, M.D., M.S., F.A.C.P.
Deputy Medical Director
Director of Professional Education

Evelyn Salerno, Pharm.D.
Consultant Pharmacist

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## HOSPICE CONCEPTS OF NARCOTIC USE IN CHRONIC PAIN CONTROL

A narcotic acts solely for pain relief. It has no effect on an underlying disease producing pain. When routinely taken as directed in a set dose according to a regular schedule, narcotics in this situation have been found to be NEITHER ADDICTING NOR DOES TOLERANCE DEVELOP — that is, there is no need to continually increase the drug dose once pain control is established and there is no tendency to develop withdrawal symptoms when the dosage is reduced gradually.

There are several theories for the absence of classic features of addiction under such circumstances:

1. Because medication is given routinely at regular intervals "around the clock" there is no pain. The "memory" of pain is erased. Therefore, there is no association of the administration of medication with the relief of pain.

2. Because the patient knows that the medication will be given continuously and will be effective in preventing pain, there are fewer anxieties about the relief of pain or whether enough medication will be given.

It is extremely important to not change the prescribed time interval between doses of narcotic. This interval is calculated to allow each new dose to start taking effect before the effect of the previous dose has worn off. The goal in treating chronic pain is to prevent the pain from even recurring, not treat it once it is again present. Therefore, when narcotics are used in this fashion, *THERE IS NO NEED FOR "FAST ACTING" PAIN MEDICATION.*

Narcotics are usually given by mouth both for reasons of convenience as well as to avoid the discomfort to the patient of repeated injections. The dose of narcotic prescribed will be the one which is found to be effective in controlling pain without sedation. Because clinical response is the index of effectiveness, THERE NEED BE *NO CONVERN ABOUT RATIOS OF DRUG ABSORBTION.* However, so that blood levels do not fluctuate too widely, it is important that the dose of narcotic not be changed any more often than every 24 to 48 hours.

Oftentimes, narcotics by mouth will be given in a solution of water or a flavored syrup. This allows more careful regulation of drug doses, e.g., within a mg per dose. Also, liquids are easier to swallow. The choice of liquid used depends upon patient flavor preferences and the basic taste of the drug.

For the patient who cannot swallow or is vomiting, suppositories can be used. *INJECTIONS ARE ALMOST NEVER NEEDED.*

*Brompton's mixture* was an analgesic mixture first used in England around 1900 in Brompton Chest Hospital. It consisted of a solution of heroin, gin, cocaine and chloroform water. It was one of the original solutions used by the first English Hospices in the 1960's for chronic pain control because it was readily available. Careful investigational studies have since shown that morphine is as effective as heroin for pain control with no difference in side effects. Cocaine provides only temporary and marginal benefit in reducing sedation with definite risk of causing hallucinations and nightmares. Gin causes sedation. Chloroform water adds nothing of benefit and is illegal in the U.S. due to cancer causing properties in mice. Hospices in England, Canada and America are currently achieving good pain control with morphine and antinauseants alone and find no need for the other ingredients contained in the original Brompton's solution.

*NOT ALL NARCOTICS ARE THE SAME.* There are ranges in strength of analgesia in therapeutic ratios, and in absorptive characteristics. Some vary according to *duration of action:* for example, Demerol and

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text of "Brochure for Care Givers"

* an interdisciplinary patient care team structured to be able to meet the whole spectrum of health care and personal needs for comfort, relief, and self-sufficiency experienced by patient/families facing the diagnosis of incurable and progressive illness with a short life expectancy.

PROGRAM COMMITMENTS

1. keep patient and family home together as much as possible
2. supplement and coordinate, not duplicate, existing service programs
3. educate health professionals and lay community
4. support the family as the unit of care, during illness and in bereavement
5. help the patient live as fully as possible, even while considered to be dying.
6. keep total costs down.

QUALIFICATIONS FOR SERVICE

1. limited prognosis, e.g. less than 12 months, due to chronic progressive illness which has been designated not curable by the primary physician (will need to be verified by hospice physician at assessment).
2. desire by patient and family for therapy oriented toward achieving optimal comfort and relief rather than disease control per se.
3. live in Dade County (or Broward County)
4. there is a primary care person, e.g. a competent individual in close physical proximity (at least within ear shot) to the patient most of the time who is willing and able to participate in patient care and assume responsibility for notifying hospice of changes in condition; does not necessarily need to be a blood or legal relative
5. three consents for hospice service, e.g. patient; primary care person, and primary physician, who all acknowledge the above and are willing to work as a part of the hospice team.

HOSPICE SERVICE PROGRAMS

1. total care plan
2. bereavement care

Pending: (a) symptom control consultation
(b) relative consultation
(c) bereavement consultation
(d) inpatient unit for symptom control and temporary family respite

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# HOSPICE, INC.

PROGRAM CHARACTERISTICS

* care oriented toward meeting total needs.

  ---physical symptoms, e.g. pain, nausea, confusion, dyspnea, etc.
  ---physical signs, e.g. ulceration, decubiti, bowel obstruction, etc.
  ---intellectual needs, e.g. need to know, need to participate in care, need for kind truth, need to correct misconceptions about disease and prognosis and signs/symptoms to expect and care availability and effectiveness, etc.
  ---emotional strain, e.g. worry, grief, bereavement, etc.
  ---social disruption, e.g. family, friends, job secondary to both disease and its therapy, etc.
  ---financial fears, e.g. loss of income, cost of treatments, family future, etc.
  ---spiritual concerns, e.g. questions of why, meaning, significance,etc.

*continuum of service under centralized administration.

  ---patient and family together are the focus of care.
  ---integration of professional and nonprofessional elements of care.
  ---coordination of inpatient (hospital) and home care.
  ---coordination of other community services with hospice and primary physician services.
  ---availability of service to patients on program, 24 hours a day, 7 days a week.
  ---bereavement support for family.

* interdisciplinary patient care team care.

  ---core team: acts as a unit with internal autonomy but always in consultation to the primary physician.

    * home care nursing
    * social services - financial counseling
      - psychosocial support
      -bereavement support
    * physician services
    * volunteers - home care
      - administrative
      - speakers bureau
      - bereavement
    * clergy

  ---role blurring
  ---self-ministering and supportive
  ---contract services - physical therapy
    - occupational therapy
    - speech therapy
    - respiratory therapy
    - recreational therapy

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# HOSPICE, INC.

* an interdisciplinary patient care team structured to be able to meet the whole spectrum of health care and personal needs for comfort, relief and self-sufficiency experienced by patient/families facing the diagnosis of incurable and progressive illness with a short life expectancy.

STAFF POSITIONS

| | |
|---|---|
| Home care nurse | o primary figure in identifying patient and family needs (medical, emotional, physical, social, etc.) at home<br>o central figure in maintaining both medical and personal aspects of home care.<br>o establish continuity of care by maintaining contact with family during first week of bereavement. |
| Social worker | o direct casework service to patient and family financial assessment and counseling<br>o psychosocial support services<br>o team support services |
| Hospice physician | o interdisciplinary team training and supervision in medical care<br>o interdisciplinary team support and consultation in care delivery<br>o direct patient care in consultation to primary physician<br>o around the clock availability of on call physician services for home bound patients<br>o administrative support<br>o clinical research and reporting |
| Patient care Team Director | o supervise home care nurses<br>o be contact person for home care patient related calls<br>o coordinate all elements of program in provision of home care<br>o coordinate program with other community services involved with patients on hospice program<br>o keep patient charts up to date with all services provided and patient/family needs<br>o supervise weekly interdisciplinary patient care team meetings |
| Volunteer Director | o be responsible for screening, training and support of volunteers.<br>o supervise volunteer performance |
| Follow-up director | o be responsible for various bereavement service programs<br>o coordinate and supervise persons involved with provision of bereavement care. |

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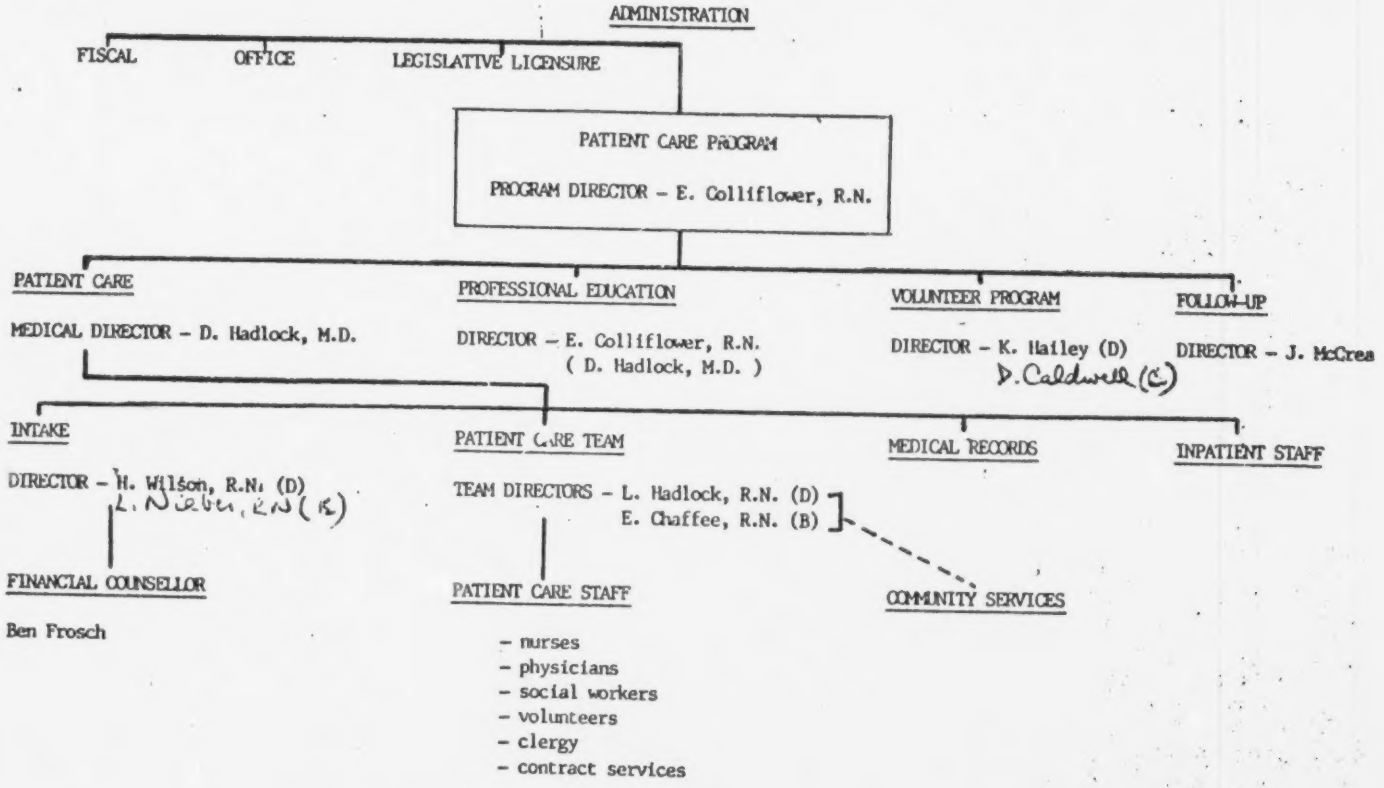


1/29/82

# HOSPICE, INC.

CASE PRESENTATION — INITIAL ASSESSMENT.

Date of admission: 16 November 1981

62 WMM

referred by hospital social worker

Diagnoses: carcinoma of the lung
pathologic fracture of T12

Presenting problems: back pain
hallucinations
stomatitis
constipation
family disruption

CASE PRESENTATION — SERVICES PERFORMED

Management of medications:

analgesics - methadone
"Brompton's"
ASA

antinauseants - Thorazine
Compazine

bowel regimen - Surfak

antitumor - Procarbazine

other - Tagamet
Slow K
prednisone
Nizoral

**Miami:**
111 N.W. 10 Ave., Miami, Fla. 33128 • (305) 325-0245

# HOSPICE, INC.

CASE PRESENTATION — SERVICES PERFORMED

New problems: depression
immobility
dyspnea on exertion
family anxiety
flatus

Community agencies: oxygen

Family conference.

Nurse was present at the time of death.

Respite services.

CASE PRESENTATION — DISCHARGE SUMMARY

Admission date: 16 November 1981

Discharge date: 4 January 1982

Reason for discharge: death

Location at discharge: home

Total days on program — 50

(all days on program spent at home)

Total patient/family/staff contacts — 39

Contacts per hospice staff discipline:

| | |
|---|---|
| RN | 18 |
| MD | 1 |
| SW | 1 |
| aide | 17 |
| homemaker | 2 |

Basic to provision of all services was a 24 hour a day, 7 day a week availability of service in addition to regularly scheduled visits as needed.

Family is currently being followed on the bereavement program.

Miami:
111 N.W. 10 Ave., Miami, Fla. 33128 • (305) 325-0245

STATEMENTS OF SARAH ANN HACKETT, R.N., M.P.H., EXECUTIVE DIRECTOR, CAMBRIDGE VISITING NURSING ASSOCIATION; CAROL L. HOLDEN, R.N., B.S., HOSPICE CARE COORDINATOR, HOSPICE OF CAMBRIDGE; AND KRISTINA SNYDER, M. ED., ADMINISTRATIVE COORDINATOR, HOSPICE OF CAMBRIDGE

## INTRODUCTION

At no other time in recent history have groups of consumers and concerned citizens so profoundly influenced health care delivery. Hospice developed as a humane community response to the treatment of dying patients and their families. It is a grassroots movement which is influencing the medical professions and raising the awareness and acceptance of dying people and their needs.

The scope and nature of the hospice philosophy of care are well documented and will not be covered in this testimony. Each community develops and defines its own program based on existing resources. We will concentrate on the Hospice of Cambridge, in existence since September 1980.

## HISTORY OF PLANNING AND DEVELOPMENT OF THE HOSPICE OF CAMBRIDGE

The Hospice of Cambridge is a program of the Cambridge Visiting Nursing Association, a nonprofit, certified home health agency which has been serving the Cambridge community since 1904. The Cambridge VNA provides multiple services to any resident of Cambridge regardless of ability to pay.

The planning and formation of the Hospice of Cambridge as a new program was fairly unique. The Cambridge VNA began meeting with OMEGA, a volunteer grief assistance program, in November 1979, and from the very beginning both groups were concerned about not creating another bureaucracy or institution. Instead of forming a "new" program with a new organization and staff, the planning group looked at the existing groups in Cambridge and decided that the community is especially rich in services. Some groups and hospitals were giving aspects of hospice care already. A collaborative approach was established, with the Cambridge VNA designated as coordinator of the program because of its experience and certified status as a home health agency. The Cambridge VNA Board of Directors enthusiastically supported the development of such a program.

## DESCRIPTION OF HOSPICE OF CAMBRIDGE

Medical professionals and lay personnel form an interdisciplinary team. Members include, but are not limited to, the following: the patient and patient's family, the attending physician, hospice physician, hospice nurse, clergy, social worker, mental health and trained volunteer. They are available 24 hours a day, 365 days a year. Hospice staff also includes coordinators for hospice care, administration, bereavement, and volunteers. Specialized therapies such as physical therapy, occupation therapy, nutrition, speech therapy may also be included on the team as the needs of the patient dictate.

A group of physicians who staff the Primary Care Unit at Cambridge Hospital function as hospice back-up physicians. They are on call 24 hours a day and make home visits when needed. The patient's private physician is encouraged to join the care team, but if that is not possible, the hospice physicians are available. The assurance of a home visit from a physician is an invaluable addition to the type of comprehensive care that a terminally ill patient and family needs.

Highly committed and trained volunteers play an integral part. Hospice of Cambridge contracts with a hospice volunteer training group, Omega. The volunteers function as befrienders. There is also a need for direct service volunteers who will do shopping, housework, offer transportation and respite sitting to enable the family to go out or rest. Each hospice uses volunteers in a slightly different manner based on the community and patient needs.

The availability of inpatient hospice beds is a necessary back-up to comprehensive hospice care. Youville Hospital, a chronic care and rehabilitation hospital with a long tradition of terminal care, has a contractual agreement with the program. Even with major home supports that hospice can provide, it is not possible for every family to participate in the death of a family member. Hospice does not limit dying to the home. It allows the patient and family to choose where death occurs.

Hospice addresses the physiological, psychological, educational, social, spiritual, and other special needs of the patient and family experienced during dying, death, and through bereavement. No one profession or group can meet these total needs of patient and family, therefore the interdisciplinary team approach is essential. A

doctor or nurse is not always appropriate or trained to deal with spiritual pain or complex family dynamics.

SUMMARY OF FIRST YEAR STATISTICS SEPT. 1, 1980–AUG. 31, 1981

87 patients—average age 65. Diagnosis: 73 cancer, 12 cardiac, 1 vascular, 1 Parkinson's.

62 patients died—33 died at home; 19 died in acute care hospital (includes in transit to emergency room and pronoucements on arrival); 10 died at Youville hospice inpatient beds.

7 patients discharged from program.

Average length of stay for everyone enrolled during September 1, 1980–August 31, 1981—65 days.

Average length of stay for people who died before August 31, 1981—50.5 days.

493 days hospitalized (including Youville) for every patient enrolled in program—7.4 day/per patient.

Average number for hospitalized people—14.5 days.

Total cost per patient—$2050[1]—$32 per day (excluding hospitalization); 324 hours volunteers—3.7 hr/per patient.

Average length of hospice nurse visit—2 hrs/per visit (includes prep and post and travel time).

Average length of bereavement visit—2.3 hrs/per visit (including p & p, trav.).

Sources of reimbursement: Medicare—57.1 percent; free—14.9 percent (4.5 bereavement and 10.4 percent hospital assessment); Medicaid—10.7 percent; Blue Cross CHHC—7.3 percent; Blue Cross Grant—3.3 percent; other—3.1 percent; full pay—1.9 percent; Blue Cross—1.5 percent; and VA—0.2 percent.

COST OF CARE AND REIMBURSEMENT

As a program of a certified home health agency, skilled nursing, specialized therapies, and limited home health aide coverage are reimbursed. This is only partial reimbursement for all the services required in hospice care. The fiscal intermediary in Massachusetts for Medicare has very recently severely limited the number of reimbursable home health aide hours to 100 hours per month per client. This comes to 3 hours, 7 days per week. In order to provide patient care and family support some patients require 24-hours per day of home health aide services. This applies particularly to elderly couples who are both infirm and to single persons who have no family. The current cost of home health aide services in our area is $8.39 per hour. Most families cannot afford to pay privately. The obvious result of this limiting decision is hospitalization whether or not the patient or family wish or need it. The place of death ought to be a conscious individual choice not a dictate of reimbursement.

COST OF CARE COMPARISONS FROM THE FIRST YEAR OF OPERATION SEPTEMBER 1, 1980–AUGUST 31, 1981

*Home care:* Average cost $32 per day; total cost per patient $2,050

*Extended Care Facility:* Average cost $55–$75 per day (N.B. The patients we care for exceed the level of care in nursing homes; i.e., more than 3 hours of hands-on care a day.)

*Chronic Disease and Rehabilitation Hospital:* The cost of one day in Youville Hospital, the chronic disease and rehabilitation hospital we contract with, is approximately $145 per day.

*Acute Care Hospital:* The average rate for room and board alone in Greater Boston area acute-care hospitals is $250–$350 per day. The last figures do not include any ancillary service cost. These could raise the total to $430 a day.

Emergency room visits for symptom control have decreased due to the availability of 24-hour hospice care. With very few exceptions, symptom-control procedures can be done as well at home as in a hospital. This is due to the specialized training in pain and symptom control of hospice physicians and nurses.

Currently, our program is operating at a loss because not all services provided by hospice are reimbursable by third-party payors. The two major examples are: hospital assessment visits and bereavement followup visits.

Visits to the hospital to plan discharge include the patient and family and are essential in planning good care. The purpose is to allay anxiety and smoothe the

[1] The total cost per patient for noncancer patients (13.6% of total caseload) was $2,101.34 (excluding hospitalization).

transition from the acute-care setting to the home and to set up supportive services and medical equipment if needed. Knowing what to expect, allows the patient and family to work cooperatively toward their goals.

In traditional health care, when the patient dies all supports to the family are terminated. Many studies have shown that family member death rates are significantly higher within the first year after a loss. This is often attributed to the "broken heart syndrome." To help prevent the serious consequences of grief and to provide support in this critical time, hospice offers a multifaceted approach to bereavement: support groups, counseling, nursing follow-up visits, and self-help groups.

CONCLUSION

One hundred and fifty patients and families have been served during the past year and a half of hospice care. Referrals are equally divided between the Cambridge VNA, hospitals, physicians, and patients/families. This clearly demonstrates that such a service is needed and appreciated (see attached two letters from families). In Massachusetts alone there are 35 hospice programs serving 185 communities, most of which developed in the last three years. The hospice movement will not go away.

We urge a favorable committee report on HR 5180. Rarely in this time of scarce resources and competing demands will members of Congress have a better opportunity to provide so much help at so little cost.

[Attachments have been retained in the subcommittee files.]

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HOSPICE OF DAYTON, INC.,
908 SOUTH MAIN STREET,
*Dayton, Ohio, March 19, 1982.*

ANDY JACOBS,
*Chairman, Health Subcommittee,*
*House Ways and Means,*
*Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: I am enclosing a sample of the letters we sent to Senators Metzenbaum and Glenn, and Representatives Hall, Brown, and Kindness requesting their support of Senate Bill 1958 and House Bill 5180.

I am also enclosing copies of the responses I received from each of them. Please include my supportive letter as testimony to be included in the Committee report.

Sincerely yours,

BETTY L. SCHMOLL, R.N., M.S.,
*Executive director.*

HOSPICE OF DAYTON, INC.,
908 SOUTH MAIN STREET,
*Dayton, Ohio, January 12, 1982.*

HOWARD METZENBAUM,
*Senator, U.S. Senate,*
*Congress of the United States, Washington, D.C.*

DEAR SENATOR METZENBAUM: Senate Bill 1958 has been introduced and we would like you to consider signing on as co-sponsor of the bill. The National Hospice Organization Education Steering Committee will be contacting you to discuss the bill, and we hope you will give them time.

Hospice of Dayton, Inc. has made a significant contribution to the Greater Dayton community since its beginning in September, 1978. More than 750 dying patients and their families have received care; community appreciation and support has been generous; and the program has provided compassionate, cost-effective care.

If you can visit our program and go into the home of one of our families, we will be honored to make the arrangements. Your support for Hospice reimbursement is important to us and to our community.

Sincerely yours,

BETTY L. SCHMOLL, R.N., M.S.,
*Executive Director.*

CONGRESS OF THE UNITED STATES,
HOUSE OF REPRESENTATIVES,
*January 21, 1982.*

BETTY L. SCHMOLL, R.N., M.S.,
*Executive Director, Hospice of Dayton, Inc.,*
*South Main Street, Dayton, Ohio.*

DEAR BETTY: I have received your recent message concerning S. 1958. Thank you for contacting me about this.

I appreciate getting your thoughts on this matter. It is always helpful to me to get the thoughts and comments of people of our area on the many issues and policy considerations of concern to the Congress.

I look forward to hearing from you again about this program.

Sincerely yours,

THOMAS N. KINDNESS,
*Member of Congress.*

CONGRESS OF THE UNITED STATES,
HOUSE OF REPRESENTATIVES,
*Washington, D.C., March 1, 1982.*

MS. BETTY L. SCHMOLL,
*Executive Director, Hospice of Dayton, Inc.,*
*South Main Street, Dayton, Ohio.*

DEAR MS. SCHMOLL: I want to thank you for writing to express your support for S. 1985, legislation to provide for the full Medicare reimbursement for hospice services. I appreciate being advised of your interest in this legislation.

At present, S. 1958 is pending in the Senate Finance Committee. To date, no hearings on the measure have been scheduled. You might be interested to learn, however, that similar legislation has been introduced in the House of Representatives. This bill, H.R. 5180, is pending in the House Ways and Means Committee. It is my understanding that the committee plans to begin hearings on this measure during the first part of this month. I intend to monitor these considerations and I shall certainly keep the thoughts you have expressed in mind should this bill come before the full House of Representatives for a vote.

I wish to thank you again, Ms. Schmoll, for bringing your interest in this bill to my attention. I do hope that you will continue to advise me of your thoughts on matters of concern to you.

Best wishes.

Sincerely,

TONY P. HALL,
*Member of Congress.*

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
*Washington, D.C., March 5, 1982.*

MS. BETTY L. SCHMOLL,
*Executive Director, Hospice of Dayton, Inc.*
*908 South Main Street, Dayton, Ohio.*

DEAR MS. SCHMOLL: Thank you for your letter concerning S. 1958, a bill to provide for hospice reimbursement. I appreciate hearing from you.

I strongly support the expansion of Medicare coverage to hospice care. Hospice care provides a compassionate and cost-effective alternative for terminally ill patients and their families. S. 1958 appears to be an important effort to encourage the use and development of hospice programs instead of the current practice of penalizing participants—both patients and hospice facilities.

Several hospice organizations in Ohio have raised some technical questions that S. 1958 might create problems in its present form. I support this bill as a vehicle to bring about much-needed changes in hospice reimbursement, and I will work with other Senators to make the technical changes necessary to meet the valid concerns of certain existing hospice organizations.

Again, thank you for sharing your concerns with me.

Very sincerely yours,

HOWARD M. METZENBAUM,
*U.S. Senator.*

U.S. SENATE,
*Washington, D.C., February 22, 1982.*

Ms. BETTY SCHMOLL,
*Hospice of Dayton,*
*South Main Street, Dayton, Ohio.*

DEAR MS. SCHMOLL: Thank you for advising me of your support for legislation to provide for coverage of hospice care under the Medicare program (S. 1958 and H.R. 5180). This legislation would allow Medicare-eligible Americans an opportunity to choose between either hospice or traditional treatment for terminal illnesses.

Like you, I am sympathetic and concerned with the needs and desires of those who are terminally ill. I believe we should support the right of these patients to receive the type care they desire, and I was glad to add my name as a cosponsor of S. 1958.

Please be assured that I will continue to follow congressional actions on this important issue with your thoughts and concerns in mind.

Best regards.

Sincerely,

JOHN GLENN,
*U.S. Senator.*

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HOSPICE OF MARIN,
*San Rafael, Calif.*

Hon. ANDY JACOBS, Jr.
*Chairman, Subcommittee on Health of the Committee on Ways and Means, House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. JACOBS: As the Executive Director of one of the oldest hospice programs in the United States, I have prepared the following information as favorable support for bill HR 5180. Incorporated in 1975 and beginning services to patient/families in 1976, Hospice of Marin was one of the earliest programs in the United States. In timing, we followed closely after the development of the Hospice of Connecticut and with them soom became leaders of the hospice movement in this country, providing education and sharing experience and expertise with newer programs.

Marin County has a population of 211,500 and records approximately 400 cancer deaths a year. Hospice of Marin is currently providing services for almost one third of the patient/families in which death from cancer occurs. We have been actively delivering patient care for six full years and to date have provided care for almost 700 families. The average family unit has 3.5 members which means that well over 2,000 people have received quality care that is:

1. more comprehensive,
2. of better quality, and
3. less expensive than existing alternatives.

The families served by Hospice of Marin have had the opportunity to receive appropriate care for their disease and support that has been responsive to the comprehensive need of the family unit. The inappropriateness of hospitalization for a terminally ill individual who needs specialized care and support has become obvious to all of us. Our files are filled with testimony from families who support the concept, who confirm the benefit by speaking first hand about what hospice care meant for them—what that care meant for them physically, psychologically, and financially.

When Hospice of Marin began providing home care 30 percent of the people we cared for were able to stay at home. The other 70 percent were still dying within an acute facility structure. Over time we have been able to reverse that statistic and now 70 percent of the people served by Hospice of Marin die at home while only 30 percent die within an acute facility. Hospice of Marin does not have a hospice inpatient unit at the present time.

Originally it was intended that we would develop an inpatient facility similar to those in England and Connecticut, which were the models for our program. While the desire for hospice inpatient care in Marin remains strong, we have been unable to complete plans for development of such care either through a free-standing hospice or through negotiations with existing facilities. The lack of adequate reimbursement is a significant impediment.

As one of the pioneers in the delivery of care we have been intensely aware of the deficiencies in reimbursement for hospice services. The amount of money that could be received from the existing reimbursement system was totally inadequate for the overall care required. Initially we felt it was inappropriate to try to fit a fragile and embryonic program into the sridct control and structure of the Medicare system. Since only a small part of the cost of the service provided could be recovered we chose not to risk jeopardizing our principles of care by trying to comply with inappropriate bureaucratic control. Consequently, the Hospice of Marin Board of Directors decided early on that to bill within the existing structure would be not only inappropriate but also possibly detrimental to the successful development of the Hospice of Marin program. The quality and comprehensiveness of the hospice services were the number one priority. The need to provide the care, to develop the program, and to obtain community and medical endorsement was critical. We succeeded in that effort beautifully.

In an attempt to develop a coordinated continuous system of care for terminally ill patients, Hospice of Marin contracted with a group of health care consultants who explored alternatives for providing inpatient services to hospice patients. Consutlants S/B/O Associates provided the following information.

"Based upon a study of trends in hospice care, population forecasts and disease rates, there is a need for an inpatient residential unit of six beds for Hospice of Marin. Our study of the issues, especially those related to the difficulties of licensure, certification, and reimbursement by third party insurers, leads us to recommend that Hospice of Marin not begin immediately with the construction or operation of an inpatient residential facility but proceed with carefully planned steps to that end."

As a result the Hospice of Marin home care patients in need of inpatient care must continue to use the existing acute care facilities at a daily cost that is much greater than any hospice inpatient cost per day in the country.

Hospice of Marin has had opportunity to participate in the federal demonstration project. The services provided within that framework are adequate and extremely appropriate. The service definitions that exist today for the federal project are the result of work by the HCFA staff as well as the directors of a number of the California programs. Therefore, I speak with knowledge and understanding about the services required for appropriate hospice care and I am comfortable that those services are adequately provided for within the parameters of the legislation introduced.

It is important to stress the qualities of hospice care that set it apart from traditional care of the terminally ill. Hospice care is far more comprehensive, addressig the full range of needs of patient and family. Through special training, staff develops expertise in minimizing pain and the symptoms of advanced disease, supporting the patient during the unfamiliar and frightening experience, of dying, helping the family develop a strong network of support, and preparing the family for the eventual void in the family system. Services are available 24 hours a day, and staff develops an intricate internal system of communication so that fragmentation of care and inappropriate emergency response from existing acute care systems not occur. In order to illustrate how hospice care helps family members as well as the patient, I am including a profile of a hypothetical but typical family (Attachment A).

Hospice of Marin program needs continue to grow. Hospice of Marin has become a sound, solid, and important part of the community in which we reside. We are now making plans to bill the existing system for the home care services that are covered. But the existing Medicare system will allow Hospice of Marin to retrieve only 77 percent of its cost for those services presently covered. We are unable to obtain through Medicare 33 percent of the cost of covered services not to mention the costs of the uncovered services of bereavement, emotional support and counsel, the volunteer training, supervisory and managment costs.

The volunteer effort remains a strong component of the Hospice of Marin program. For your information I have attached the year-end statistics for 1981 for the patient care staff and volunteer staff as well (Attachment B). As you can see, very careful detailed records are maintained for all volunteer activities at Hospice of Marin. Provision of volunteer labor is an exceptional contribution and should be acknowledged to the community as well as to the volunteers providing the care. Volunteers provide practical support and in-kind contribution of labor. But, more importantly, they bring the community into the hospice program. Programs have been developed because they have been responsive to community needs and this is an important aspect of our development, coordination of service, and community support. Volunteer service must remain a part of every hospice program. It is a supplemental service of assistance that enriches the quality of each individual program. While it is important to acknowledge the benefit of such service and the financial suport

to administer this program, it is equally impoortant to acknowledge the inappropriateness of billing specifically for volunteer service. I feel quite confident that a safeguard can be created to ensure that individual programs not attempt to obtain compensation for volunteer visits once there is a mechanism in place for hospice reimbursement.

Examples of the services that patient care volunteers can provide include:
Relief for the family member who is the primary caregiver
Help to maintain a safe environment by doing simple household chores
Help with meal preparation
Shop for groceries
Transport patient to a doctor's office or other appointment
Provide child care
Provide comfort and support through visits to patients' homes, convalescent homes or hospitals.

Hospice home care patients are acutely ill. Many would need hospitalization if the hospice program did not exist. Over one third of the Hospice of Marin admissions during 1982 came directly from the hospitals. The discharge of these individuals to home was dependent on the simultaneous admission to Hospice. Many of the others admitted to Hospice of Marin during this same time period were admitted in order to avoid or delay admission to a hospital.

The physicians and families evaluating the quality of Hospice of Marin's services have provided outstanding endorsement of the program services and the significant importance of the services. From September 1977 through June 1980, an independent consultant focused on determining the degree of satisfaction experienced by patients, families, and physicians who have used Hospice of Marin's service (Attachment C).

There is a relationship between emotions and illness, and human emotions play a significant role in the cause of illness. In San Francisco there was recently a two-day seminar on this subject sponsored by the Department of Psychiatry of the University of California. It was attended by 150 mental health experts. Evidence was presented by Dr. George Solomon that stress can alter the function of the body's immune system. Dr. Craig Van Dyke, a co-director of the conference and an associate professor of psychiatry at UCSF, discussed how the loss of a loved one can suppress the immune system. He went on to state, "Bereavement is used as a model for understanding the relationship between emotions and illness because it is common, universal, and probably the severest stress anyone goes through. Nobody understands how or why, but bereaved people suffer more physical ailments and higher rates of mortality."

Studies reflect that during the period of grief following a death, surviving family members are particularly vulnerable to the onset of illness, the misuse of drugs or alcohol, and strain within the family sufficient to cause breakup. The hospice program allows for support and direction during this critical time when people are more susceptible to disease and illness. The program offered by a number of hospices within the HCFA 26 (including the Marin program) includes only minimal bereavement care. Ideally we would like to have a fuller and more comprehensive program. In October 1980, when the HCFA project began, we realized we had to compromise on this issue. Three bereavement visits for some individuals is quite adequate and for others not nearly enough. Nevertheless, within those constraints, we can develop a professional bereavement support program that allows for variation. One-to-one counseling, group support work, education presentations, practical workshops, and social events are examples of the kinds of service that we have offered during our years in hospice work. While the limitation to three bereavement visits concerns many professionals, it does at least allow for assessment, evaluation, volunteer support and/or referral to another source. It is important to follow through with a family even for this limited period. Hospice programs which wish to develop longer bereavement support can do so with community funds and/or volunteers. It is irresponsible to withdraw from the family following the death until their ability to cope and readjustment has been evaluated.

Funding to date for the Hospice of Marin program has been obtained through the efforts of hard working board, staff, and community. It is now critical that a reimbursement system be designed to cover the services provided by a hospice program. The funders who have enthusiastically supported Hospice of Marin development and program refinement are no longer able or willing to absorb the total cost of these services.

Not only has Hospice of Marin been a provider of services in Marin County California but we have been training people nationally for almost five years. Over 1,200 people have attended the Hospice of Marin training programs. Evidence that hos-

pice care is different from traditional terminal care is apparent by the demand for training from those wishing to learn how to provide hospice services. The need for professionals to develop and sharpen skills in this area has long been apparent to Hospice of Marin. We have aided the development of hospice programs across the United States and have shared with people our knowledge and expertise, seeing to it that they learned as much as possible about the principles and practice of such care. This training was provided in response to the demand put on us by potential providers all across the united States. People wanted to know more about the delivery of care and needed to know how to set up the programs in their respective areas. Attachment D outlines the responses Hospice of Marin has made to those requesting the opportunity to study hospice care.

Hospice care is in demand. It is in demand because it is a service that adequately addresses the medical, psychological, social, spiritual, and practical needs of people when all else around them appears useless and hopeless.

The cost savings that can be realized by this method of care have been adequately described in the document commissioned by the Warner-Lambert Foundation (November 1981) A Summary and Statement of Conclusions of Cost and Fiscal Impact Analysis of Proposed National Hospice Reimbursement Bill.

IN SUMMARY

Community support expressed through contributions from foundations, corporations, and individuals has aided hospice development nationally, but

The providers of the early financial support for this Hospice program development have now moved on to support other types of innovative programs, and

Adequate reimbursement from third party payors for hospice care is not yet a reality.

The gap in funding caused by the latter two factors threatens continuation of hospice services as presently defined. It is imperative that legislative action occur soon. To delay decision in this matter will threaten the national availability of services and encourage continuation of inappropriate higher priced medical care.

I appreciate the time you have taken to familiarize yourself with the hospice philosophy and practice and to review this document. I have taken the liberty of attaining a sampling of the letters received by Hospice of Marin in support of our program when funding was requested from a local foundation. I am available to assist with this important work and offer my time and expertise to aid in the favorable consideration of this legislation.

Very truly yours,

MARY TAVERNA, RN,
*Executive Director.*

Enclosures.

[Attachment A]

HOSPICE OF MARIN

PROFILE OF A TYPICAL FAMILY UNDER HOSPICE CARE

*The patient.*—Male, 55 years old. After a successful business career in which he was accustomed to being in charge, this man now finds that his disease has progressed to the point that he has had to give up his job and cannot do many things for himself. His many physical symptoms (including pain and weakness) are increasing the feelings of helplessness he is experiencing, his concern about the burden he is placing on his family, and his inability to talk openly about this. As a result, he is withdrawing further every day. His appetite is diminishing, his physical pain is increasing, his frustration is growing, his outlook is dark. He is adamant about staying home until his death.

*Wife of the patient.*—53 years old, employed. She is the primary caregiver, the one responsible for seeing that her husband receives the care prescribed, the one who feels she must "keep up his spirits." At the same time, concern about income after his death makes her reluctant to quit a very good job with promotion possibilities. She is also unsure that she will be able to provide for his physical care at home. She is dealing with feelings of being afraid about the future, ashamed to find she is angry at her husband for "doing this" to her and the children, exhausted by all the physical and emotional demands.

*Daughter.*—Age 24, married with two small children. Demands of her young family, reluctance of her husband to visit or deal directly with the fact of her father

dying, feelings of guilt for not helping her mother more, are taking a toll of this young woman.

*Son.*—Age 19, in college. He is torn between wanting to leave school and come home to help and be with his father and wanting to carry out his father's wish that he continue and succeed in preparation for his chosen career. He does not want to stir things up by suggesting he stop school for awhile.

*Daughter.*—Age 12, at home. This pre-teen is struggling with the problems of her own identity while trying to assimilate and deal with all the implications of her father's dying, her mother's heavy burden. She is a "good girl" and does not want to complicate her parents' lives by expressing the tumult she is experiencing.

The Hospice of Marin nurse assigned to make the initial visit would do a thorough evaluation of the patient's condition. The nurse would work with the patient's primary physician in developing a plan for medical treatment. She, or the social worker, would also assess the patient's emotional state and need for intervention. The treatment plan would be discussed fully with the patient and the family, giving them opportunity to make decisions, giving the patient some sense of control over his life. Evaluation of the family's resources to provide the needed care and open discussion of their feelings about that will "clear the air" to some extent, diffusing resentments and help in the development of a plan for assistance.

Those patient care tasks for which the family feel they can assume responsibility will be taught by the Hospice of Marin nurse. They will learn how to do them and how to know if and when more help is needed. The nurse will be available by phone 24 hours a day, seven days a week, a fact that greatly diminishes stress.

Involvement of the Hospice of Marin counselor or social worker in family counseling sessions would aid in bringing all of the family members, including the grandchildren and son-in-law, into a setting where open discussion of fears, concerns, feelings of guilt, etc., could be very productive.

The college-age son might make clear his fear that no one will let him know in time for him to come home to spend the last few days with his father. Being assured he will know in time frees him to continue his classes for now.

The pre-teen shows evidence of enough turmoil that arrangements might be made for her to meet one-to-one with the counselor to explore and learn to deal with her feelings, questions, and other areas of concern.

The process has begun. Each visit by the nurse will bring about a re-evaluation of all of these factors. Continued contact by the counselor with appropriate family members can facilitate open communication and encourage expression of feelings. This repeated contact and professional service aids family members so they can cope better, live more productively, use this time to better advantage, and then survive the death in a healthier manner.

[Attachment B]

## YEAR END VISIT STATISTICS, DECEMBER 1981

| Patient care | Visits | Hours (actual time) | Average time per visit |
|---|---|---|---|
| Nursing | 1,508 | 1,710 | 1.1 |
| Home health aide | 805 | 1,368 | 1.7 |
| Homemaker | 488 | 1,848 | 3.8 |
| Continuous care | 65 | 564 | 8.7 |
| Home respite | 12 | 66 | 5.5 |
| Bereavement | 237 | 312 | 1.3 |
| Family counseling | 209 | 225 | 1 |
| Total | 3,324 | 6,093 | |

*Year end volunteer statistics*

| | |
|---|---|
| Average number of regular active volunteers per month: | |
| Office | 3 |
| Phone | 12 |
| Patient care | 8 |
| Speakers bureau | 5 |
| Total | 28 |

| | |
|---|---|
| Speakers bureau: | |
| Number of assignments | 46 |
| Hours at assignment | 64 |
| Travel time hours | 31 |
| Preparation time | 84 |
| Total hours | 179 |
| Year end total number of hours in office: | |
| Phone | 1,776 |
| Typists/general office | 186 |
| Memorial donations volunteers | 173 |
| Training | 4 |
| Mailings | 378 |
| Mailing list | 75 |
| Total | 2,592 |

| Patient care volunteer visits | Number | Hours |
|---|---|---|
| Acute hospital | 14 | 8 |
| Convalescent facility | 56 | 77 |
| Home | 186 | 453 |
| Funeral/memorial service | 1 | 1 |
| Bereavement (home) | 19 | 59 |
| Phone calls | 28 | 25 |
| Travel time | | 140 |
| Total | 304 | 763 |

*Conferences, meetings, trainings*

| | |
|---|---|
| Patient care volunteers | 298 |
| Office volunteers | 92 |
| Speakers bureau volunteers | 96 |
| Total | 486 |
| Total number of volunteer hours | 4,020 |

[Attachment C]

EVALUATION REPORT

The goal of evaluation procedures at Hospice of Marin (HOM) over the past three years has been to determine the effectiveness of the program measured in terms of consumer satisfaction. In order to determine how well HOM has been meeting its twin objectives of (1) improving the quality of life for the terminally ill patient, and (2) aiding the family in its ability to cope with the stress of caring for the patient and of facing the threat of imminent loss, questionnaire surveys have been conducted of patients, surviving family members, and physicians who have utilized HOM services.

Personal interviews were conducted with patients; questionnaires were mailed to attending physicians and survivors of HOM patients. The overwhelming majority of respondents to the three surveys reported a high degree of satisfaction with HOM services. In answer to specific questions, over 90 percent of all replies reflected the belief that hospice care had made the remaining days of life more comfortable and less stressful for the patient and had made life a great deal easier for the family in coping with the illness.

Physicians were particularly grateful for the support given to the family and reported that this had eased the burden on the doctor considerably. Family members stressed the "compassion and understanding," the "kindness and the caring" shown by HOM staff. Patients who were interviewed said that they appreciated being treated like a human being, the "feeling that you're a person, even a special person."

Specific services that were deemed to be most helpful by both physicians and families were:

24-hour availability
Regularity of home visits and nursing care
Psychological support for patient and family
Helping the patient remain at home as long as possible
Adequate pain control

As previously noted, physicians' remarks emphasized their appreciation of counseling and psychological support for the family as well as for the patient. One physician stated that it was difficult for him to stipulate which of the services provided by HOM had been most helpful "because of the implied comparmentalization of services, when in fact what was provided was a total presence embracing not only the patient and family but the doctor as well. "Your support of the entire complex through the vicissitudes of terminal illness has been of indescribable value to me and my patients."

Judging form the comments added to the questionnaires, it is apparent that the most appreciated element in hospice care is the personal attention, kindness, willingness to listen—in short, the human contact and evidence of caring. Examples of such comments from families have included "moral support," "just being there," "individualized care," "just knowing that someone cares," and "the assurance that you were there to call on."

Patients themselves expressed much the same sentiments with comments such as: "It's nice to have someone to listen." "Their concern gives you the push to keep going." "Treated as an individual, not a statistic." "Building up spirits." "Availability, reassurance, sympathy, kindness." "Just to talk to people." "Comfort and understanding—treat me like a human being." The consistency of these remarks with those made by family members indicates clearly that treating the patient as a person is most meaningful and valuable to the terminally ill patient and his family.

In conclusion, the evidence from the surveys shows plainly that the humanistic approach, recognition of the patient's feelings as well as his body, does indeed make a difference, and that Hospice of Marin has been demonstrably successful in meeting the objective of improving the quality of life for both patient and family.

Detailed data supporting this report are available at Hospice of Marin

JO ANN KLUTCH,
*Evaluation Consultant.*

[Attachment D]

HOSPICE OF MARIN INFORMATION AND EDUCATION PROGRAM—1977-1981

PROFESSIONAL INFORMATION, EDUCATION, AND TRAINING PROGRAM

(For physicians, nurses, social workers, counselors, clergy, administrators, board members, and others)

22 five-day training seminars held in Marin County, California.—429 hospice professionals from 41 states, Washington, D.C., and Canada.

Conferences and courses.—841 in attendance at 20 different conferences and courses in Marin County, other California sites, and in other states.

Consultations and informational visits at hospice of Marin.—118 visits by individuals or groups from 27 states, 6 foreign countries.

On-site presentations by Hospice of Marin staff.—85 presentations in 13 states.

Hospice of Marin Information handbooks sold.—(Between November 15, 1980 and December 30, 1981): 275 handbooks sold in 49 states and in 3 foreign countries.

PUBLIC INFORMATION AND EDUCATION

*Media*

4 interviews on Bay Area radio stations
5 Bay Area television interviews
1 German television interview
1 Japanese television interview

30 articles about or mentioning Hospice of Marin in newspapers and periodicals (including *Time, Wall Street Journal,* and *Newsweek*)

Presentations by the volunteer speakers bureau.—(About hospice goals and unique services, cost effectiveness, etc.): 191 presentations in Marin County, San Francisco and neighboring Bay Area counties.

GREENBRAE, CALIF., NOVEMBER 10, 1980.

MARY TAVERNA, RN,
*Executive Director, Hospice of Marin,*
*Mark Drive No. 17, San Rafael, CA.*

DEAR MARY: I am pleased to write in support of Hospice of Marin's request for funding from the San Francisco Foundation.

Hospice has comforted and assisted in the care of dozens of my cancer patients (and their families) and its nurses have performed ably and nobly in assisting them to be cared for in their homes where they wished to remain during their final illnesses. I am convinced that in the vast majority of these patients this would not have been otherwise possible, and that no other health care service here in Marin could substitute for Hospice of Marin, and that it would be a disaster if Hospice were to perish for lack of financial support.

With best wishes,

Sincerely,

JAMES R. DAHL, M.D., F.A.C.P.

GREENBRAE, CALIF., NOVEMBER 10, 1980.

MARY TAVERNA, RN,
*Executive Director, Hospice of Marin,*
*Mark Drive, San Rafael, CA.*

DEAR MRS. TAVERNA: I understand that you are requesting funds for Hospice of Marin from the San Francisco Foundation. I would like to enthusiastically and whole-heartedly support your request, for I feel the work your organization does is fantastic.

I have been in the practice of medical oncology in the community for two years now, and you have been of the utmost service to my patients. Until Hospice of Marin became well established in our community, no one really addressed the needs of seriously ill and dying patients with malignant diseases.

As you know, I occasionally teach at the Hospice Training Meetings which are held for folks from all over the country. They come to Marin to see how an excellent Hospice program functions. At these meetings, I am constantly reminded what a wonderful organization Hospice is, and the fact that Marin's Hospice is really a unique one.

The attention that your staff gives to my patients and their families, and the time and energy spent in making them comfortable with their disease and limitations, is truly amazing. I cannot say enough on Hospice's behalf.

I certainly hope that the San Francisco Foundation will support your continuing work, and please call upon me if I can be of any help. My best wishes to you and your staff.

Sincerely yours,

PETER D. EISENBERG, M.D.

SAN RAFAEL MEDICAL GROUP,
*San Rafael, Calif., August 19, 1980.*

Re: Terminal care.
DR. WILLIAM M. LAMERS,
*Director, Hospice of Marin,*
*San Rafael, Calif.*

DEAR DR. LAMERS: I would like to express my sincere thanks, admiration, and pride in the Hospice organization and their exemplary, loving and attentive care for Robert and his entire family during his long and tortuous illness which ended from metastatic carcinoma of the kidney on August 15, 1980.

The patient and his entire family were greatly benefited by your loving care and attention.

Speaking for the entire medical profession, I would like to express our debt of gratitude to the example and service that your organization has set in helping care for this family and others with similar problems.

Best wishes in the future.

Sincerely yours,

RIPLEY H. HUNTER, M.D.,
*Attending Physician for Mr. Robert.*

HOSPICE OF MIDDLETOWN INC.,
*Middletown, Ohio, March 17, 1982.*

Subject: H.R. 5180.

Hon. ANDY JACOBS,
*Chairman of Health Subcommittee, House Ways and Means Committee, Longworth House Office Building, Washington, D.C.*

DEAR REPRESENTATIVE JACOBS; In November, 1980, Hospice of Middletown, Inc., began officially serving patients with a terminal illness and giving support to their families. The positive response from these families to the loving/professional care they have received has proven to us and to the community that the hospice concept is a valuable alternative to traditional modes of caring for the dying. The community has supported us generously for over a year with their monitary contributions as well as their volunteer time. We're well aware that many of our services are reimbursable and have therefore taken steps to become a licensed home health agency in order that we may bill Medicare, Medicaid, and some private insurance carriers.

Unfortunately, only a portion of the type of in-depth care we provide is able to be billed under current Medicare restrictions. For example, a hospice nurse may be needed in a home during a crisis for up to several hours in order to keep the patient out of an institution, but hospice would only be entitled to reimbursement for one hour of that time per visit. Those of us in the hospice movement maintain that a more comprehensive method of reimbursement for hospice services under Medicare would not only result in relieving a financial burden on the individual hospice program but would also result in a sizeable saving to the Medicare system. Home care costs of a dying cancer patient are substantially less than the exhorbitant costs of institutional care, and should be recognized as a valuable alternative for those who desire that type of care.

Because of our determination to continue to deliver hospice care in Middletown and our need to seek a more fair reimbursement system in order that we may remain financially able to continue that care, we support the current legislation which has been introduced in Congress to amend the Medicare law.

Please include my supportive letter as testimony in the committee report on H.R. 5180.

Sincerely,

JANET EHRHARDT, R.N.,
*Executive Director.*

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Subject: H.R. 5180.

Hon. ANDY JACOBS,
*Chairman, Health Subcommittee, House Ways and Means Committee, Longworth House Office Building, Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: Hospice of Middletown, Inc. began serving patients with terminal illness in November, 1980. I joined the staff in January of 1982 as a professional social worker. I have been impressed with the loving/professional care patients and families have received as a part of Hospice and as an alternative to traditional modes of caring for the dying. The quality of people's lives has certainly been improved while at the same time the number of days in a hospital has been reduced.

One difficulty we are encountering in meeting the needs of our dying patients and their families is that only a portion of our in-depth services can be billed under current Medicare restrictions. Supportive services, e.g., counseling to families of dying patients, is an important aspect of hospice philosophy and care. An example of a current restriction in Medicare payment is in the area of bereavement follow-up. Studies have shown that supportive services during the grief process aid a person in having a "normal recovery". The alternative to "normal grief" many times results in increased stress and medical problems, thus adding to individual and government medical costs.

Those of us committed to the hospice philosophy believe that a more comprehensive method of reimbursement for hospice services under Medicare would result in savings to the Medicare system by reducing days in an institution and would relieve the financial burden faced by many individual hospice programs.

Because of our belief in giving people the alternative of hospice care—"to live until you die"—we at Hospice of Middletown support the current legislation which has been introduced in Congress to amend the Medicare law.

Please include this supportive letter as testimony in the committee report on H.R. 5180.

Sincerely,

CHARLOTTE SAWYER, MSW,
*Hospice of Middletown, Ohio.*

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Hon. ANDY JACOBS,
*Chairman, Health Subcommittee, House Ways and Means Committee,*
*Longworth House Office Building, Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: I am writing to express support for H.R. 5180 regarding changes in Medicare which would cover Hospice services.

As a registered nurse working with Hospice of Middletown for the last year and a half, I have seen the needs of terminal cancer patients. These needs are not currently being met by out health care system.

Terminal patients, in most cases, can be cared for in the home by their own families. This is the best type of care. To enable families to provide home care, which is cheaper than hospital care, our Hospice offers the supportive help of nurses, social workers, physicians, clergy and volunteers. Each family is different. Some require almost 24 hour nursing care during the last phase of cancer, while others need periodic visits and emotional support. Most families require support following the death of a patient.

Because many of our current services are not reimbursable under Medicare, and because I believe our services are important and cost effective, please include my supportive letter as testimony in the committee report on H.R. 5180.

Sincerely,

DEBORAH WENDT,
*Hospice of Middletown, Ohio.*

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STATEMENT OF DOROTHY S. DORION, R.N., M.S., PROGRAM DIRECTOR, HOSPICE OF NORTHEAST FLORIDA, INC., JACKSONVILLE, FLA.

Hospice of Northeast Florida, which provides a program of care and support for the terminally ill and their families, extensively utilizing the services of volunteers, both lay and professional, wholeheartedly supports the intent of H.R. 5180. We feel that reimbursement for hospice care is properly within the scope of medicare reimbursement and is essential for the survival of hospices such as ours with a large volunteer component.

We represent a model of hospice (grass roots, community-based) which is not operating under the umbrella of a home health agency, hospital, nursing home or other health care provider, and, therefore, receives no formal reimbursement. Most of our income (we charge nothing for our services) is derived from memorials or gifts from individuals who have been touched by our program or are supportive of the hospice concept and the quality of care provided by our hospice. Although we have been operating in this manner for over 3 years, we are finding it increasingly difficult to raise funds and expand our much-needed services. Without reimbursement, such hospices as ours with an average caseload of 30 patient/families cannot continue to exist.

Despite the necessity for adequate funding, we have serious reservations about several provisions of H.R. 5180 and cannot support it in its present form. These reservations are set forth below:

1. The requirement that hospices provide services directly or though arrangement with other hospices will tend to promote the development of regional hospices or, in effect, mandate that hospices have their own inpatient facilities. The Florida Hospice statute adopted in 1979 presented us with virtually the same situation, but we have since succeeded in amending the law to permit inpatient care to be given by contract. Contracting with existing health care facilities appears to be the most cost-effective method of providing short term inpatient care, which, in our case, represents only 10% of the total days in our hospice program. We believe that the legislation should encourage such contractual arrangements which serve to integrate hospice care with that of existing providers, rather than creating yet another layer of care. The revised Florida Hospice statute could serve as a guide in this regard.

2. Where inpatient hospice care is provided by contract, reimbursement should be available either to the hospice or the health care facility delivering the inpatient care. This flexibility would further encourage and strengthen the home care portion of hospice care.

3. The role of the Medical Director must be delineated in such a manner as to preserve the involvement and integrity of the primary physician in hospice care. The primary physician should be involved in the recertification process.

4. Many requirements are set forth in the proposed legislation more properly belong in regulations.

5. The 75 percent cap may be too generous and might result in excessive costs with a net reduction in the Medicare Trust Fund. (The cap is based on costs experienced in the last six months of the lives of cancer patients, whereas the average length of stay in a hospice program is 40–50 days.)

Although reimbursement is sorely needed by Hospice of Northeast Florida and many other volunteer hospices, H.R. 5180 may be premature. There are as many unanswered questions as there are models of hospice and it may be prudent to await the outcome and evaluation of the 26 HFCA projects prior to adopting any indelible legislation. In 1979, the hospices in Florida were victimized by hastily drafted hospice legislation which was adopted without the experience of pilot programs or other appropriate evaluations. As a result, the hospice statute in Florida has undergone extensive revision in each of the three legislative sessions since adoption.

Again, let us say that we heartily endorse the concept of medicare reimbursement for hospice care and commend the Congress for taking the first step in achieving this worthy goal.

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STATEMENT OF DOROTHY MOGA, EXECUTIVE DIRECTOR, HOSPICE OF NORTHERN VIRGINIA, INC.

Hospice of Northern Virginia (Hospice) supports H.R. 5180 in the present form. We believe that it is a well constructed bill which incorporates the essence of hospice care in the U.S. and has appropriate and acceptable safeguards to control costs.

Hospice has four years of experience in providing home care and has initiated hospice inpatient care this year. We are a community based, free standing, non profit orgainzation designed solely to provide hospice services in our community. We are licensed by the Commonwealth of Virginia and certified by Medicare as a home health agency. Our inpatient facility is licensed as a hospital and Medicare certification as a hospital is currently pending in the HCFA regional office. We are one of the 26 sites in the national Medicare/Medicaid demonstration sponsored by HCFA and also participate in a hospice demonstration under the local Blue Cross plan, Group Hospitalization, Inc. (G.H.I.).

Hospice provides a full range of services and meets the definition proposed in Section 4 of H.R. 5180. A complete interdisciplinary team provides care to patients and their families according to a plan for care that is jointly developed and reviewed frequently. Care is provided in the patient's home, if it all possible, with the inpatient service available for short term stays when home care is not appropriate. Bereavement services are available to families for the year following the patient's death.

Hospice of Northern Virginia has had extraordinary support from the community. Evidence for this come in many ways, the most obvious being financial support and services provided by volunteers.

Since it began to provide care four years ago, Hospice has received $825,000, from the community for operations and $800,000, for the renovation of an elementary school into a hospice facility. With our efforts, community support is likely to continue. It now provides Hospice with funds to care for patients and families who have insufficient insurance and/or personal resources. It cannot, however, support the program on its own and reimbursement from Medicare, Medicaid and private third party payors is essential for continuation of our program.

Volunteers are an important part of Hospice and further illustrate the community's enthusiasm and support for the program. More than 200 volunteers work actively in our program providing more than 2,000 hours of work each month; and, at any one time, 50–60 are in the process of training. They provide supportive services in patient and family care, both at home and in the inpatient unit; and they work in the office, serve on committees, perform special administrative tasks, maintain the landscaped grounds, and literally carry out hundreds of other tasks. We support the provision relating to volunteers in Section 4(c)(2))(E).

Hospice home care is the basis of our program and over 700 patients and families have been served. Our experience shows that, given the full range of hospice services, it is possible to care for most terminally ill patients at home; and we support the emphasis on home care in the bill.

Selected data from our 1981 experience shows: 82.5 percent of home-care patients died at home; 15.4 percent died in acute care hospitals; only 22 percent of the total home-care population spent any time in the hospital; the average length of stay was 16.9 days; the average length of stay in the program was 43 days; the total group of home care patients received an average of 10 nursing visits, 2.5 physician visits, 1 social worker visit; 61 percent of home-care patients used the services of a home health aide with an average of 189 hours per patient; volunteers visited patients an average of 7 times; 50.7 percent of our patients were over 65 years of age; and the estimated average cost per day of providing home care in 1981 was $68.

Because of this experience, we know we are avoiding expensive acute care hospitalization for our patients. Most patients without hospice care (70 percent estimated in a recent local Blue Cross study) die in acute care facilities. In a random sample of claims in terminal, palliative acute care, the local Blue Cross (G.H.I.) found the average cost in this final admission to be $503/day.

This kind of experience in avoiding acute care hospital stays is not possible without the full range of services available. The provision of coverage for home health aides, for example, is important. In our experience, aide help in the home frequently makes the difference as to whether or not a patient can be cared for at home. Since the cost of aide service, even around the clock, is less than inpatient care, we urge that caution be exercised in placing limits on its use. The other cost controls in the bill are sufficient and artifically limiting hospice programs in terms of the mix of services that can be used in the home will have an adverse effect on both patient care and hospice programs.

Hospice inpatient care as a backup to home care is an essential component of hospice and we support the inclusion of it as a definition of a hospice program and as a covered service. Hospice of Northern Virginia had nearly four years of experience without the availability of inpatient services; and in a very real way, knows the limitations (both in terms of quality and cost) of having only a partial program of care.

The inpatient unit at Hospice which serves the Metropolitan area of Washington, D.C. is designed for short term stays when home care is not possible, and as a substitute for acute hospital care. A very careful and thorough process of assessment takes place prior to admission, and regular review thereafter, so that appropriate stays are assured. Our experience to date (since January 11, 1982) indicates that our projection is true, i.e. patients coming into our inpatient unit are very ill and requiring an acute level of care. These patients would be in an acute care hospital if hospice inpatient care were not available.

Our charge is $270 a day, which is an all inclusive rate with the exception of drugs and an occasional laboratory test. Physician services are included. This clearly compares favorably with the $503 a day cited earlier.

In these 2½ months we have admitted 27 patients. The average length of stay has been 13 days. Several patients have been cared for in the unit for a few days and have returned to their homes. Only three patients required a transfer to a full service acute care hospital and two of these patients returned to the hospice program after a very brief stay. In the month of March our occupancy was 84%.

We believe that our first few months experience with inpatient care is not unique. We expect to have relatively short lengths of stay and to continue to care for the great majority of patients at home.

In summary, we support HR 5180 as it is presently constructed. The experience of Hospice of Northern Virginia is consistent with the provisions and the intent of the bill. Its strength lies in its recognition of hospice as a unique system of care and in its comprehensiveness while still emphasizing home care.

We urge passage in this form and as quickly as possible.

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HOSPICE OF SNOHOMISH COUNTY,
*Everett, Wash., March 26, 1982.*

JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means,*
*1102 Longworth House Office Building,*
*Washington, D.C.*

DEAR MR. SALMON: We would like to take this opportunity to express our support for H.R. 5180, the Hospice Reimbursement Act. In these times of severe budgetary constraints, this bill can result in significant monetary savings to the taxpayers. Recent cost studies estimated from HHS data that the average cost incurred by Medicare A and B for a terminally ill cancer victim in the last six months of life is $7,140 in 1981. In our Hospice program in 1981 our costs per patient-family served

(these include home care costs reimbursed by Medicare) were $1,440. Sixty percent of our patients died at home. In the light of this there are, however, two important changes that we would strongly urge your committee to act upon. They are as follows:

I. Re: Attending physician should recertify, not medical director or physician member of interdisciplinary group.

Change recommended: Page 5, lines 16 through 19: "(*ii*) the second 180 day period, the individual's attending physician recertifies at the beginning of the period that the individual is terminally ill;"

In our community and in our model of Hospice care—community based and contracting with Visiting Nurse Association—it is very important that the individual's attending physician stay in charge of the care. The recertification by the hospice medical director or physician member of interdisciplinary team by-passes the primary physician responsible for the patient's care. This could disrupt the continuity of care provided to Hospice patients.

II. Re: Hospice programs having the ability to contract with other provider programs:

Change recommended: Page 11, lines 14 through 17: "(*ii*) provides for such care and services in indivuals' homes, on an out-patient basis, and on a short-term inpatient basis, directly or through arrangements with other provider programs, and"

Through contractual arrangements with other provider programs in Snohomish County, namely Visting Nurse Association and Snohomish County's five hospitals, the Hospice of Snohomish County is able to significantly hold down the costs of providing Hospice care and prevent duplication of services already available in our community. The original language in the bill would, arguably, require Hospice to contract only with other Hospice agencies instead of utilizing existing providers for components of Hospice care. Contracted Hospice staff receive specialized training, supervision, and are under the clinical direction of the Hospice Clinical Director and Medical Directors. There are no other Hospice programs in Snohomish County with which to contract. Our goals in working directly with the Visiting Nurse Association, hospitals and nursing homes is to integrate hospice concepts and services into the existing health care delivery system. This greatly enhances the quality and continuity of care provided hospice patients and their families. This will not happen if a parallel system of Hospice care is created.

Hospice care has drawn the interest and support of all segments of the Snohomish County community. In 1981, over $100,000 of contributed services were donated to our Hospice program by professional and lay volunteers representing the medical community, nursing profession, social workers, clergy, and concerned citizens from nearly every local community in the county. In addition, all five hospitals in the county are enthusiastically participating in the program.

If you have further questions or concerns regardings our position, or require further information about hospice care in Snohomish County, please call me at (206) 252–5161, or our Executive Director Kay Kukowski at (206) 8855.

In advance we thank you for your efforts on this most important legislation for hospice care.

Sincerely,

BRADFORD N. CATTLE, J.D.,
*President.*

KATHLEEN M. KUKOWSKI, M.P.H.,
*Executive Director.*

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STATEMENT OF KATHLEEN HART, M.A., DIRECTOR OF HOSPICE CARE PROGRAM, HOSPITAL HOME HEALTH CARE-HOSPICE CARE, ALBUQUERQUE, N. MEX.

HHHC—HOSPICE CARE PROGRAM DESCRIPTION AND HISTORY

Hospital Home Health Care-Hospice Care is a hospice provider of home care based services to terminally ill patients and their families, a member of the National Hospice Organization, and one of the twenty-six Health Care Financing Administration Medicare/Medicaid Demonstration sites. Through our hospice program, care to patients and families experiencing life-threatening diseases is provided by a team of professional and para-professional staff, as well as volunteers, within Hospital Home Health Care, a Medicare/Medicaid certified, JCAH accredited, and licensed hospital affiliated home health agency in Albuquerque, New Mexico. Although HHHC had been providing traditional home health services under the sponsorship

of St. Joseph Hospital and Presbyterian Hospital Center since 1973, a need was determined, in the mid 1970's for comprehensive medical and psycho-social support to terminally ill patients and their families.

Patient and family are the center of Hospice Care. The Hospice Care Team includes nursing, social service, home health technician, homemaker, administrative, and bereavement counseling personnel, as well as a part-time medical director, psychological consultant, and a volunteer chaplain. Professional staff is assisted by trained and supervised volunteers and also graduate students from local university programs. Using an interdisciplinary approach which considers the care needs of the whole person—physically, emotionally, and spiritually—the team assists patients with personal care, pain and symptom, control, and mobility and safety measures, teaching these aspects of care to family members or caregivers for the purpose of enabling the patient to remain a viable family member within his/her own home. The Hospice Care team helps patients and families deal with the financial, emotional, and spiritual issues surrounding a serious illness and its concomitant lifestyle changes, as well as provides bereavement counseling follow-up to family members after a death has occurred. An important goal of Hospice Care is the provision of high quality, comprehensive medical and psychologically supportive care at all times, including twenty-four hour access to an on-call nurse.

### HCFA DEMONSTRATION PROJECT IMPACT

In 1979 the agency was selected to participate in the HCFA Hospice Demonstration Project, The demonstration, in effect since Octover 1980, has supported not only the growth of this hospice program in terms of increased staff and provision of additional contracted services, but also in terms of effective implementation of standards of care which well represent hospice philosophy, respecting the individuality and rights of dying persons and their families. With the demonstration and the additional services for which it provides reimbursement, we have been able to make available a complete interdisciplinary team, which has included bereavement care, increased psychological and medical consultation, implementation of an expanded range of group support and educational offerings for the team, and resources for coordination and acceleration of the hospice volunteer component.

During the first year of the demonstration project we served an average monthly census of 65 patients, with this year showing an increase ranging from between 75 and 95 patients per month. Seventy percent of our hospice patients are demonstration participants, patients with prognoses of less than six months. Seventy percent of the demonstration participants' deaths occurred in the home, contrasting with fifty-two percent of the total non-demonstration patients who died at home. Although we realize that at this time we have only correlational evidence, we attribute the difference in location of death to the additional services provided through the demonstration.

We have also seen an increase in average length of stay during the first year of the demonstration, increasing from a figure of 34 days for all patients and 44 days for demonstration patients, to a current ALOS figure of 68 days for all patients. We attribute this both to the fact that patients are, appropriately, being referred to us earlier, and also to the home health aide services we are able to provide which assist them in remaining at home.

Community, hospital, and physician support continues to be excellent, with seven hospitals and over 90 physicians now referring patients to the program. While the majority of patients admitted have a diagnosis of cancer (82%), with major sites being lung or breast, the program serves patients with other life threatening illnessess, including pulmonary, cardiac, renal, as well as neuromuscular diseases.

### HOSPICE IN THE CONTINUUM OF CARE—HOW OUR HOSPICE PROGRAM FUNCTIONS WITHIN A HOME HEALTH AGENCY

As part of a home health agency which has formed a hospice unit and supported the hospice concept—palliative and supportive treatment when curative measures are no longer useful—we feel that we can speak well to the need for recognition of hospice care as a distinct and necessarily separate part of the health care continuum. Our hospice team resulted from the realization that a special type of care was necessary for a population which existed and had needs different from and beyond those of the convalescing patient. In our agency there has been a clear understanding and acceptance of the time and circumstances under which a patient and family are ready for hospice care. Referrals flow well from the regular home care teams to the hospice care team, acknowledging a well-developed sense of which patients are indeed appropriate for hospice care. Another advantage of the demonstration is its

support of follow-up by the hospice team, when the patient is hospitalized for a brief period. This hospice team follow-up improves communication with hospital staffs and results in greater continuity of care.

THE COST EFFECTIVENESS CONCEPT: OUR EXPERIENCE

The major challenge confronting the hospice movement today may well be economic in nature. While we are aware that hospice does work for our patients, and that it is a humane and socially conscious treatment alternative for treatment of dying patients, we, as well as all hospice programs, are faced with the issue of financial viability. Despite the existence of hospice benefits under some insurance coverages, and continued reliance upon philanthropic and volunteer contributions, we see third party coverage in the form of a Medicare option as essential.

Our statistics over the first fifteen months of the HCFA Demonstration Project speak favorably to the cost effectiveness of a home care based hospice program such as our own. The average cost per demonstration patient, including patients with non-cancer diagnoses, has been $640 per month. This figure includes all professional services provided by the hospice care team, as well as contracted nursing aide services, in-home continuous or respite care when deemed medically necessary, medical equipment, prescriptions related to primary diagnosis, and bereavement care follow-up. As stated previously, average length of stay for our demonstration patients in particular has increased, which we would project as effecting a reduction in costs in terms of reduced hospital stays.

With response to the possible "expense" of the proposd reimbursement legislation, it would seem that the cap feature contained within the proposed hospice bill would assure that hospice care would not cost any more than it now costs to care for terminally ill patients, and would in fact ensure a significant savings to the Medicare trust fund. Providers who can remain under the proposed caps would recover costs, those who could not contain costs could opt to drop their hospice provider certification.

CONCLUSION AND RECOMMENDATION FOR SUPPORT OF H.R. 5180

What we are seeing, with regard to all segments of the Albuquerque community and its surrounding rural areas, is an increased awareness of the special care needs of dying individuals and their families. And while our experience brings home the cultural and ethnic differences between the responses and customs surrounding illness, death, and bereavement, it reflects a marked commonality in the need for high quality, costs-saving, and psychologically supportive home-based care for terminal patients from all backgrounds.

We are, more than ever, aware of an unmet need for training and support for the professionals who serve dying patients, as well as for our direct support to patients themselves. We are witnessing an accelerated demand for information and education from hospital and nursing home staffs, and church and community organizations, as well as hospice programs throughout the Southwest. Our Hospice Care team has made a commitment to meet this need through on-going education and programs on both public and professional levels.

In order for us to continue to offer the quality and scope of care we now provide, as well as serve as a model of hospice care and respond to community needs, we require acceptance and reimbursement within the Medicare system. the New Mexico State Legislature has recognized this need through passage of a House Joint Memorial Resolution urging Congress to adopt reimbursement legislation. We ask that the House of Representatives support HR 5180, which would allow Medicare beneficiaries to choose this timely and proven treatment alternative.

THE LEGISLATURE OF THE STATE OF NEW MEXICO, 35TH LEGISLATURE, 2D SESSION, HOUSE JOINT MEMORIAL 12—INTRODUCED BY REPRESENTATIVE MAX COLL, REPRESENTATIVE LEO D. CATANACH, REPRESENTATIVE BEN LUJAN, AND REPRESENTATIVE SILAS T. GARCIA

A joint memorial urging Congress to adopt legislation incorporating hospice benefit for medicare eligibles

Whereas, the needs of the terminally ill and their families in New Mexico and the nation have not been adequately met by the health care delivery system; and

Whereas, the hospice concept of care for the terminally ill and bereaved and their families has received worldwide acclaim because of the efforts to deliver such care first in England under the leadership of Dr. Cicely Saunders; and

Whereas, in the United States, the needs of the terminally ill of all ages were first brought to the attention of health professionals and the general public by Dr. Elizabeth Kubler-Ross; and

Whereas, through the efforts of many volunteers and health professionals, the hospice program of care has become an accepted part of the health care delivery system; and

Whereas, the hospice program of care has received the official endorsement of such organizations as the American Medical Association and the AFL-CIO; and

Whereas, the hospice program of care is now being accepted by the public and private insurance industry, including the Metropolitan Insurance Company, the Travelers, the Equitable Life Assurance Society, Connecticut Blue Cross/Blue Shield and the Connecticut Life Insurance Company, to name but a few; and

Whereas, a number of national corporations have provided the hospice benefit to their employees' dependents and in some cases their retirees, examples of such corporations being General Electric, Westinghouse, Warner-Lambert Foundation (New Jersey, RCA and the National Cancer Institute); and

Whereas, a large number of terminally ill patients and their families fall under the provisions of medicare for financial assistance; and

Whereas, an actuarial study commissioned by the Warner-Lambert Foundation clearly indicates that the incorporation of the hospice benefit for medicare eligibles, as currently defined, will bring about significant savings to medicare; and

Whereas, hospices in New Mexico are participating in the areas of education, training and program development and in the setting of standards for the quality of care; and

Whereas, these standards are also for the well-being of the terminally ill living in the state of New Mexico; and

Whereas, the legislation proposed to modify medicare benefits in the national congress is also in the interest of New Mexico residents; Now, therefore, be it

*Resolved by the Legislature of the State of New Mexico* that the standards proposed for the quality of care in the hospice program are appropriate and necessary to the organization and delivery of care for the terminally ill and their families in New Mexico and that the congress of the United States is therefore urged to adopt national legislation incorporating the hospice benefit for medicare eligibles; and

*Be it further resolved that a copy of this memorial be sent to each member of the New Mexico congressional delegation and to the appropriate clerks of the United States Senate and the United States House of Representatives.*

C. GENE SAMBERSON,
*Speaker, House of Representatives.*
ALBERT ROMERO,
*Chief Clerk, House of Representatives.*
ROBERTO A. MONDRAGON,
*President, Senate.*
JUANITA PINO,
*Chief Clerk, Senate.*

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STATEMENT OF ARTHUR KNOWLTON, M.D., DIRECTOR, RADIATION THERAPY CENTER, HOSPITAL OF ST. RAPHAEL, NEW HAVEN, CONN.

Honorable Chairman Jacobs and distinguished members. My name is Dr. Arthur Knowlton, and I am the Director of the Radiation Therapy Center at the Hospital of St. Raphael in New Haven, Connecticut.

In my practice, which consists exclusively of patients with cancer, I see approximately 450 new patients with cancer each year. Over one-half of these patients will go on to die from their disease. I look upon Hospice as a new development in medicine; a stride forward in the management of a patient with cancer. Examples of great achievement in medicine have been the discovery of antibiotics to combat infection and modern cardiac surgery which saves thousands of lives each day with the implantation of valves and new blood vessels. Likewise, in the total management of a patient with cancer, a new dimension has been added to those fortunate to live within the service area of a true Hospice organization.

We have always had mechanisms to treat cancer, either in a curative way or by attempting to relieve the symptoms caused by it. But until recently, we have had no

mechanism to attend to the dying aspect of this disease with Hospice care available, it is possible to plan from the very beginning the total management of a patient with cancer. Total care of the cancer patient involves the initiation of surgery, radiation, other forms of therapy and finally and most importantly, when these modalities have failed, Hospice intervention on a home care basis. The management of these patients does not consist of holding their hand, administering consoling words and watching them die in misery. It is going to the home when the patient is able to remain there and dealing with the everyday problems of living of both the patient and the family. Such problems are pain, decreased appetite and weight loss, weakness, difficulty moving ones bowels, sleeping, the sadness and despair of the patient and family.

The Hospice personnel have the ability and expertise to work closely with the family and are of great assistance to the patient at home. Our Hospice facility operates 24 hours a day, 7 days a week. Other Hospice-like groups within the State of Connecticut are closed after 5 PM and closed on weekends. My patients frequently call Hospice for help on Saturdays, Sundays, and in the middle of the night. The patient who is cared for by the Hospice home care team feels that there is someone who is interacting with him on an individual basis—someone he may call anytime of day or night.

As the patient deteriorates, further steps must be planned for his management. Although many families are able to manage such a patient for a day or two, they do not realize what is involved in the total care of a bedridden, dying patient at home. They cannot spend 24 hours a day carrying and lifting the patient out of bed into the bathroom, feeding the patient, washing the patient, and taking total care of all the needs of a dying patient. If it becomes necessary to move the patient to the Hospice inpatient facility, I have never yet had a family regret making such a move. The inpatient facility must have and, in our area, does have a large ratio of personnel per patient. Patients are not treated as they are in an acute hospital on a 4-hourly basis for pain medication, with 3 meals a day at 7, 11, and 4 o'clock, but as an individual. Their pain medication is brought at the time it is needed and in between times as necessary. They individually see the dietician, The patients are fed individually and administered to so that their last dying days are spent in as much comfort as possible.

An acute care hospital is not the place, at the present time, for a patient dying of cancer. Such patients are neglected by the house staff because the house staff cannot learn from them. The house staff is interested in a patient with an acute heart attack or in a rare type of pneumonitis. Likewise, the nurses who are few, are tied up with the sick patients for whom there is hope and the poor dying patient with cancer is left alone in his bed badly neglected. I have often seen meal trays placed before such patients and taken away without being touched because the dying patient did not have the strength to feed himself.

Hospice, however, has a different outlook on such patients. Their total orientation is to care for the individual who is dying. They spend time with him; they make sure he is pain-free and make sure his family can come and visit whenever they wish. They help feed the patient and look after his needs. The patient is sure that someone with much expertise in treating his problems is caring for him.

To sum up, it is my feeling that Hospice is something new in the total management of the patient with cancer. Hospice should be involved early on in the management of those patients who cannot be cured of their disease. The patient should initially start on a home care program and, as needed, be taken to the inpatient facility for the dying event. We must insure that Hospice consists of well-educated and trained and motivated people possessing the expertise to manage patients dying of cancer.

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STATEMENT OF TAMMY S. JOHNSON, WICHITA, KANS.

Mr. Chairman and distinguished members of the Subcommittee on Health:

I am Tammy S. Johnson, a Licensed Baccaulaureate Social Worker in the State of Kansas.

I would like to thank you for the opportunity to express my views regarding Medicare coverage of hospice services for the terminally ill.

Based on my experiences as a social worker in direct services with the elderly and terminally ill, I enthusiastically support enactment of H.R. 5180 for the following reasons:

1. The bill expands needed services to the elderly and terminally ill and provides a broader range of alternatives to institutional care.

2. The terminally ill have special needs which are not always met in hospitals or nursing homes. This bill addresses these needs.

3. H.R. 5180 emphasizes the provision of supportive services to the dying rather than the construction of new facilities specifically for the terminally ill.

As a social worker I have had personal contact with many terminally ill patients and their families. I would like to present my views regarding what I see as inappropriateness of our existing health care delivery system in providing for the needs of the terminally ill. A selection of cases of terminally ill individuals with whom I have had contact will be presented to show how these people might have benefitted if they would have had access to hospice services.

### NEEDS OF THE TERMINALLY ILL

Our society is slowly beginning to reassess attitudes toward death and dying. We have begun to understand that death, like birth, is a natural part of the life cycle. There is also a growing recognition that a cure of disease is not always possible, and that exhaustive efforts to prolong life are sometimes not in the best interest of the individual.

Increasingly, we as a society are recognizing that the terminally ill have special needs.

Quality of life is a difficult concept to measure, but most would agree that it would include respect and dignity of the individual, freedom from unnecessary pain, and the right to self-determination.

In most cases hospitals and nursing homes are not structured in ways which would allow them to effectively meet the needs of the terminally ill and their families. Hospital staff are primarily concerned with the prevention and treatment of acute illnesses. Because of their emphasis on cure, there is often a tendency for the staff, reflecting their own attitudes toward death and dying, to withdraw from contact with the patient. the sterile atmosphere of a hospital, isolation of the patient and depersonalized attitude of personnel, combined with the daily routine of the hospital can serve to make one's final days very lonely.

While long-term care facilities generally provide a more home-like environment, most have characteristics of a total institution. Because of the size of most of these institutions, and certain regulations governing them, a fairly rigid schedule is adhered to concerning meals and patient care. Lack of privacy or personal space is common. In most cases staff members do not have appropriate training or the time to devote to the special needs of the dying.

When an individual has been diagnosed as terminal, it is common practice for a hospital to transfer the patient to a long-term care facility. It is also common for the nursing home to return that same patient to the hospital when death becomes imminent.

### CASE STUDIES

The following cases of terminally ill patients are examples of how our present system of health care delviery is inadequate in meeting the special needs of the dying. The names have been changed to protect the identities of their families.

### CASE NARRATIVE NO. 1

Bill M., a frail, fifty year old, former construction worker was admitted to a local hospital in September of 1981 to receive treatment for a chronic drinking problem. During a routine examination in November, doctors discovered that Mr. M. had an advanced case of lung cancer which was inoperable. The doctors advised him of his condition and explained to him that he had approximatey three months to live. At that time one of the social workers at the hospital began looking for a long-term care facility where Mr. M could spend the remainder of his days. He was admitted to a nursing home in another town late in the day on Christmas Eve, 1981. He had $25.00 which was given to him by staff at the hospital, and a grovery sack containing his personal belongings. Due to the fact that the nursing home was near capacity, the only room available for Mr. M was located in the heavy care wing of the facility. It is in this area that the most severely physically handicapped and mentally confused elderly residents reside. Due to these circumstances Mr. M spent most of his day, including mealtimes, surrounded by an extremely depressing environment, especially for a man who was dying of cancer.

Although Mr. M had no family, he maintained close contact with his ex-wife, who visited him on a regular basis.

At the time of his admission Bill expressed bitterness and anger regarding his prognosis. He seemed to have a strong need for some in-depth counseling by someone who had training in working with the terminally ill.

Despite the fact that the staff at the nursing home was very interested in minimizing his pain and maximizing his comfort, the structure of the facility did not permit him to have any control over his life. He was denied privacy or the right to make decisions about his treatment. Mr. M, a very independent man, was most upset about having to ask for a cigarette when ever he wanted to smoke. He expressed despair to me in facing long, boring days spent with regressed residents. When his death became imminent, he was transferred to a hospital in town to die.

In summary, he died a lonely death, having been shuttled between nursing home and hospital.

This case illustrates the inappropriateness of institutional care for the terminally ill and the need for Medicare reimbursement of hospice care.

CASE NARRATIVE NO 2

Betty L., a seventy-five year old woman, was admitted to a nursing home with a diagnosis of lung cancer. She was aware of her prognosis and had a need to talk with someone about her feelings regarding her condition. Mrs. L was also in need of spiritual support. Her family had difficulty accepting the grim prognosis and were in need of much support.

As her condition deteriorated, Mrs. L became afraid of falling asleep and requested that someone stay with her at all times. Her family worked and could not be with her during the day and the staff at the nursing home did not have the time to spend with her as she requested.

As she became weaker and more physically incapacitated, she often expressed feelings of anger and embarrassment at her inability to care for her personal needs.

Before her death Mrs. L. requested the presence of her minister. She died approximately thirty minutes after his visit.

In this situation a hospice program could have provided this patient and her family with physical and spiritual support in their time of crises.

CASE NARRATIVE NO. 3

Marie A., an eighty-five year old resident of an intermediate care facility, was diagnosed as having cancer of the bladder. As her condition deteriorated, she remained mentally alert and expressed the desire for death to take its natural course and hoped that she would die in her sleep. When she became unable to tolerate solid food, she was transferred to a skilled nursing facility where she was kept alive against her wishes by tube feedings. A short time after her admission she lapsed into a coma and died.

In each of these cases a supportive, appropriate environment which stressed control of pain, respect and dignity for the individual, and the right to self-determination would have aided their transition from life to death. Retaining control, having personal belongings, familiar surroundings, individual attention to personal needs for comfort, counseling, and spiritual support are important for the terminally ill.

The hospice alternative presents a more humanistic means of serving the terminally ill and their families.

Medicare reimbursement for hospice would make this service an alternative for those who would otherwise not have access to this type of health care. Expansion of coverage would provide more appropriate health care to the terminally ill at a lower cost than that provided by hospitals and nursing homes.

Currently there are several programs providing various forms of hospice care in the State of Kansas. I have included articles from local newspapers citing specific cases where hospice care has helped the terminally ill in our community.

SUMMARY

In conclusion, the hospice alternative has been proven to be an effective means of providing appropriate, quality care for the terminally ill. However, a national hospice program for all disabled and elderly terminally ill persons will not be a reality until hospice care coverage is included under the Medicare program. I urge your passage of H.R. 5180.

Thank you.

### Statement of Hon. Thomas N. Kindness, a Representative in Congress From the State of Ohio

Thank you for this opportunity to appear before the Subcommittee on Health of the House Committee on Ways and Means.

Mr. Chairman, briefly, I'd like to make two points concerning H.R. 5180, the "Hospice Care Reimbursement Act."

First, the proposal is a sensible one. The legislation before you would permit Medicare reimbursement for hospice care for terminally ill patients under an arrangement that

Is desirable for both the patient and the family,

Is less costly to the patient than hospitalization,

Is less expensive for the taxpayers in terms of Medicare's health care coverage, and

Relieves upward pressure on hospital health care costs.

The legislation is drafted to assure cost-effectiveness. It will not add any new beneficiaries to the Medicare rolls; it will, in fact, tend to reduce Medicare costs and may help to avert forced reductions in other Medicare services.

Second, the creativity, responsibility and responsiveness characterized by this proposal demonstrate that meeting social welfare needs does not necessarily require that the federal government spend more or even the same amount of money. Each year at this time there is a chorus of warning that any cutback in spending or readjustment in current services will automatically translate into less service of lower quality. The legislation before you would both readjust current practice and result in a lower level of expenditures; and it would at the same time result in additional service of a more desirable nature.

Over the last year, I've visited with people involved in providing hospice services in several areas in my district in Ohio. The appeal of future hospice programs in small towns and rural areas there is particularly strong, since hospital care facilities may be located some distance away, while families and patients receiving proper assistance through hospice care can cope with the circumstances of a terminal illness in the familiar surroundings of their homes. Hospitalized terminally ill patients are confined to what by necessity has been a rather sterile physical and emotional environment. I am particularly impressed with the nature of services offered by hospices, the quality of are, and the cost-saving available to the patients.

Let's make those savings available to more patients and their families, and to the taxpayers as well. I urge your prompt and favorable consideration of H.R. 5180.

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### Statement of Hon. Robert T. Matsui, a Representative in Congress From the State of California

Mr. Chairman, I would like to take this opportunity to thank the distinguished gentelman from California, Mr. Panetta, for introducing this important legislation. I am especially pleased to speak in favor of this measue given the significant beneficial results that have accrued through the broad utilization of the hospice concept in the Sacramento region. The evidence developed through this actual field experience demonstrates clearly that the hospice concept not only represents one of the most humane and sensitive health care delivery systems for the dying, but it represents a sound economic model by which to curb skyrocketing health care costs. I would like to share with the committee a brief summary of the Sacramento experience.

Three years ago the Greater Sacramento Cancer Council (GSCC) began working in the area of hospice coordination. The GSCC staff recognized a growing community-demand for the development of hospice providers and supportive care service agencies in an effort to coordinate future hospice program efforts. GSCC prepared the first Hospice Status Report for our area and sought and received funding from the Junior League of Sacramento which assisted the Sacramento Cancer Council in the coordination of hospice activities and provision of in service hospice care programs.

The umbrella organization which has evolved is known as the Hospice Community Group. It consists of representatives of an eight-county area in Northern California, comprising some 8,558 square mile including El Dorado, Nevada, Placer, Sacramento, Sierra, Sutter, Yolo, and Yuba counties. The area has a total population of approximately 1.2 million. These counties represent rural as well as urban communities.

One of the most humane aspects of the hospice concept is the opportunity for the terminally ill patient to remain with his family during the last days of his life and not be isolated in tertiary health care facilities in distant urban cities. The Hospice

Community Group has complemented his goal by the establishment of ten regional hospices in its eight-county area. The scope of faclities range from acute care hospital to convalescent nursing homes to home support assistance. A regional network of health are providers and volunteers has been established to service the needs of the patients the hospices seek to serve.

One of the most fascinating aspects of the hospiecs movemet in the Sacramento region is the extensive cooperation among the individual programs. Over the past year, most hospice volunteers have been trained in a community-wide training course cosponsored by Sacramento City College and Sacramento's six hospice programs. It is this spirit of cooperation and the mutual sharing of resources which enhances the delivery of humane care to the terminally ill.

At my result, the Sutter Community Hospital/Visiting Nurse Association has provided specific figures as to the cost-effectiveness of their hospice program. In 1981, Suter/VNA program cared for 105 families at a cost of $43.60 per patient/day with a 53.5 percent home death rate. As a result there was a net reduction of 963 acute hospital days for participating families. Even adding hospice costs on to traditional costs, the approximate savings are in excess of $90,000 for the 105 patient-families served. Sixty-six percent of these patients were Medicare eligible, only one was without any coverage. These saving, if they were translated on a national scale, could significantly reduce present health care costs.

Indeed, the potential cost savings generated by hospice programs is being studied by numerous national orgainzations as the cost of care for the average terminally ill cancer patient is now approaching more than $7,000, with much of this cost constituting a Medicare expenditure. The National Cancer Institute conducted a three-year demonstration project to study the costs of hospice care and concluded the highest cost for any hospice program they reviewed averaged less than $4,500 per patient/family. Moreover, an average day of hospice care has been found to cost one-fifth of the average day of care for the terminally ill in the typical American hospital.

The Greater Sacramento Cancer Council and a task force representing the Hospice Community Group have reviewed H.R. 5180 and have endorsed its goals. These groups have asked me to make the following specific recommendations for incorporation in this hospice legislation:

(a) *Hospice concept.*—The combination of team care, continuity, utilization of volunteers and home support make the hospice concept a unique model of care. Given that the economic benefits of a hospice are founded on this integrated delivery model, it is vital that H.R. 5180 preserve the team concept.

(b) *Non-duplication.*—While some duplication of administrative, licensing or accreditation procedures may be necessary to protect hospices' uniqueness, every effort should be made to avoid creating a new bureaucracy that would potentially generate many regulatory problems while significantly eroding the cost benefits which a hospice can offer.

(c) *Homemaker services.*—The reimbursement of homemaker services is fundamental if the hospice concept is to work. Homemakers often serve as the primary provider of care to the home-bound patient and their services must be recognized by Medicare.

Hospice has become a significant alternative to the traditional manner in which we have addressed the needs of the dying. Without some adequate reimbursement mechanism, such as that proposed in this legislation, the future of hospice care is doubtful at best. It would be an unalterable tragedy if a financial mechanism is not provided to ensure the continuation of the hospice movement. Few other health care delivery programs combine such demonstrated cost savings with a humane, modern and responsible approach to treating terminally ill patients and their families. H.R. 5180 will ensure its future.

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STATEMENT OF MICHAEL P. ROSEN, ADMINISTRATOR, METHODIST HOSPITAL HOSPICE, JACKSONVILLE, FLA.

Methodist Hospital Hospice is a hospital- and home health agency-based program providing inpatient, outpatient and home care services. Located in Jacksonville, Florida, the hospice serves five counties, encompassing both urban and rural areas. Since its inception in June of 1980, the program has admitted more than 600 patients and their families. The hospice consists of an 18-bed inpatient facility which comprises an entire floor in one of several buildings on the campus of Methodist Hospital. It is fully integrated into the ancillary service pattern of the institution and can be said to exist as an integral part of the acute care setting of the hospital,

while retaining the administrative autonomy necessary to implement a true hospice environment. The home care component is coordinated through a home health agency which is managed by a regional management firm associated with the hospital. The combined hospice program staff consists of an administrator, two half-time physicians, a patient/family care coordinator, an admissions facilitator, a psychologist, a chaplain, two social workers, ten staff registered nurse positions, four licensed practical nurses, home health aides, clerical support staff, a director of volunteers, and over 100 lay and professional volunteers. The program is licensed by the State of Florida and, as far as we know, was the first hospice in the nation to be licensed under a state statute designed expressly to provide for hospice licensure. We have carefully studied the provisions of HB 5180, and it is our view that the bill is a well-conceived and thoughtful approach to reimbursement for hospice services to Medicare beneficiaries. Although we are a hospital-based program, the major thrust of our efforts is in the area of home care, where established hospice standards indicate it should be. Therefore, we are pleased that the bill places primary emphasis on this component of care. Specifically, we support reimbursement formulae in the bill which produce a counterincentive to overutilization of expensive inpatient services. In our program we currently have about five days of home care to one day of inpatient care. At this rate, we will be able to adequately fund the program under the provisions of HB 5180. However, a hospice program without such an emphasis on home care would have difficulties unless it strengthened its home care component. For example, a hospice with an inpatient to home care ratio of 1:1 or even 1:2 would incur a much higher average cost per case, which would place them over the proposed cost limits. This is not to say that certain programs should not develop such inpatient-oriented service packages; rather it is our view that the excess costs associated with such hospices should not be reimbursed by Medicare, neither should federal law and policy be designed to encourage such development. HB 5180 appropriately avoids this problem while still providing adequate cost-based reimbursement.

Much has been said about the bill's provision calling for election of the hospice benefit to the exclusion of certain other Medicare covered services. It is our view that this election process is not only workable, but essential if hospice is not to become an "add-on" to the existing health care delivery system, but rather to develop as a cost-effective, comprehensive alternative. It is true that some patients will wish to revoke their selection of hospice care and some patients will require terminal care services not provided directly by the hospice program. It is our experience, however, that this occurs infrequently and presents no significant financial problems. The alternative, a ping-ponging of patients between hospices and traditional providers, would be both inconsistent with hospice philosophy, and would produce higher costs to the Medicare program. We do feel that the added flexibility of four 90-day election periods in lieu of two 180-day periods would be of benefit to certain patients for whom the final decision for hospice care may be difficult.

Having operated since inception as a state licensed hospice, we fully support the concept of hospice licensure in all states. We also feel that accreditation could prove a useful tool in quality assurance. However in the absence of both licensure and accreditation, it will be important to ensure appropriate standards through the certification processes which will result from this legislation. It is our hope that the Congress will monitor the development of the hospice Medicare Conditions of Participation which will be used as the nationwide certification instrument.

Mr. Chairman, it is a difficult transition from hospice as a well received concept to hospice as a well defined set of eligibility criteria, reimbursable services and reimbursement mechanisms. It is a transition which would be unrealistic to assume will be without certain controversy. Some hospice programs will view the legislation as non-optimal for their individual programs. Some traditional providers may wish to bury this bill out of anti-competitive motivations. Some will want a broader benefit than is financially responsible. And others may fear the dilution of the hospice philosophy as hospice care is made widely available. We at Methodist Hospital Hospice see HB 5180 as a sensible, responsible middle ground. It contains incentives to full use of the hospice as an alternative, disincentives to overutilization of the more costly components, safeguards for quality of care, reasonable spending limits coupled with the standard cost-based reimbursement system, an adequate array of covered services, and definite but not overly restrictive eligibility requirements.

HB 5180 is good legislation, and it deserves your committee's support.

Thank you for the opportunity to make our views part of the record of this hearing.

STATEMENT OF JOANNE ASSAD, R.N., C.E.N., RECORDING SECRETARY, METROPOLITAN HOSPITAL UNIT LOCAL 2160—UAW, DETROIT, MICH.

The R.N.'s of the Metropolitan Hospital Unit of Local 2160—UAW wish to make it a matter of Congressional record that we wholeheartedly support House Bill, H.R. 5180.

It is imperative that this bill be passed to provide the means by which our patients will be able to receive the gift of death with compassion and dignity.

It will afford us the use of hospital beds for the actually ill that these patients otherwise use because they do not have coverage for Hospice care. Hospice care provides the support of Professionals to the family members and the patients, helping to keep family units intact in their final days, thereby continuing to the end quality Health Care, at a fraction of the cost.

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METROPOLITAN WEST-HOSPITAL,
JOY ROAD HEALTH CENTER,
*Westland, Mich., March 19, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: At the request of Congressman William D. Ford I am writing to you to urge the House Ways and Means Committee to vote yes on H.R. 5180 to permit Medicare reimbursement so that more people can take advantage of the hospice care program.

Terminally ill patients should have the option of living out the remainder of their lives in peace and dignity.

Not only is hospice care in many instances a more compassionate approach, it is also far more cost effective in a time when hospital costs have escalated so significantly.

Sincerely yours,

URSULA T. SOMERA, R.N.,
*Administrator.*

[Identical letters were received from: Elizabeth Fraser (and 5 others); Rose-Marie Krzywada, Redford, Mich.; Bernard J. Krzywada, Sr., Redford, Mich.; Feliciano Somera, Dearborn Heights, Mich.]

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OGEECHEE HOME HEALTH AGENCY,
*Statesboro, Ga., March 18, 1982.*

Hon. ANDY JACOBS, Jr.
*Representative, U.S. Congress,*
*Longworth Office Building, Washington, D.C.*

DEAR SIR: Hospice Bill HR 5180 proposes the establishment of hospice care under Medicare. Speaking against the hospice bill must be dissociated from speaking for the concept of caring for the terminally ill in their homes, if possible. Caring for the terminally ill in their homes is what home health nurses and visiting nurses have done historically. When Medicare legislation originally passed, inflation was relatively non-existent, and home health agencies were reimbursed for the care of terminally ill clients at home. Indeed as a staff nurse I spent considerable time visiting such patients, teaching and supporting their families and friends and visiting even after the death of the patient to assist the family in its grief reaction. This all was common practice in home health agencies.

What happened to cause a problem?

Inflation. Costs escalated and Medicare became more restrictive, writing regulations that restricted home health agencies and particularly curtailed visits to terminally ill clients. Medicare requires that skilled nursing care be given to the terminally ill. While the nurse is teaching the family, the care would be considered skilled under Medicare regulations. After an appropriate length of time for teaching, which varies according to Medicare fiscal intermediaries, the client/family is considered taught or unteachable. Then the continued assistance, using aides to bathe the client, using nurses to provide emotional support for the family is considered non-covered care by Medicare, even as the client is sicker and more in need of this basic care.

HCFA can change its regulations to include care of terminally ill clients in their own homes by home health agencies without new legislation setting up a whole new

health care system, i.e., hospices. The emotional and supportive care provided by a nurse employed by a home health agency is a skilled service. A client who is terminally ill is acutely ill. The regulations can be changed to state this.

At the present time there are demonstration hospice programs funded. The results of these programs have not been documented. Costs that we have heard about have ranged from $23 per day to $180 per day. Organized hospices frequently compare their costs to those of hospital care, pointing out that they are less costly. Hospice care costs need to be compared to home health care costs, since much of the care is carried out in the home.

Some hospices adhere to the national standards, requiring full-time paid medical directors, even though clients have their own doctors, and full-time paid clergy and clergymen employed to train other clergy in hospice work. The national standards also require autonomous agencies—precluding their cooperative functioning with home health agencies.

Before enacting legislation that sets up another layer of health care providers, please examine the means to include care for terminally ill clients in their homes under the already established, and regulated by cost caps, home health agencies. Thank you .

Sincerely,

NORMA I. HALLEY, R.N., M.S.
*Executive Director.*

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STATEMENT OF HON. RICHARD L. OTTINGER, IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Chairman, I am so pleased that this subcommittee is looking into the issue of hospice care and allowing its coverage by Medicare. The needs of terminally ill patients are an extremely crucial matter not dealt with sufficiently by existing American health care systems. Both these patients and their families deserve special attention in order to provide them with the means to make available care at home and better co-ordinated in-patient facilities.

I have co-sponsored H.R. 5180 to allow hospice care reimbursement so that it can be a realistic option for anyone who wants to receive it. Under this bill, a Medicare beneficiary who has six months or less to live may choose hospice care if the patient and the physician determine that further curative measures will not lengthen life. This way the terminally ill can avoid feelings of helplessness, isolation, and economic dependency. Better relief will be garnered from physical and mental pain and discomfort.

A major obstacle to the use of hospice care in the U.S. is funding. Most insurance programs pay for the more expensive hospitalization of the dying, but not for comprehensive hospice care. An independent study by Health Policy Alternatives, Inc. of Washington, D.C., compared costs of caring for the terminally ill in hospitals under the Medicare system with the costs of hospice services.

This study found that an average day of hospice care costs one-fourth to one-fifth that of an average day of hospital care for cancer patients. Using data from the Health Care Financing Administration, the study concluded that it now costs, in 1981 dollars, more than $7000 in Medicare benefits per patient to provide hospital care for the average cancer patient in the last six months of life. Even the most expensive combination of services under a hospice program—including physicians, nurses, social workers, drugs, medical appliances, inpatient and outpatient care, home care, and bereavement service for the family—is estimated at only $4500 per patient. In other words, patients get better care and more comprehensive services at less cost.

The cost analysis concluded that adding hospice care to Medicare would save at least $13 million in the first year after enactment and as much as $130 million in the fifth year.

Hospice care helps these patients to live out their lives in a much more fulfilling, satisfying style. It is important that the U.S. sets a precedent of respecting those who know their time is limited and want to enjoy a positive experience.

The only N.Y. State certified hospice program is in my district in Westchester County. I am very pleased to report that it has helped over 100 patients and their families, and that it is highly regarded and in great demand. It is imperative that anyone who would benefit from it be allowed to do so.

The argument for Medicare reimbursement for hospice care is made best by one who knows first hand its excellent results as an alternative. I would like to include a statement from the President of United Hospital, Kenneth Adamec.

UNITED HOSPITAL,
*Port Chester, N.Y., March 4, 1982.*

Hon. RICHARD L. OTTINGER,
*Congress of the United States,*
*2241 Rayburn House Office Building, Washington, D.C.*

DEAR DICK: On January 1, 1980, Westchester County's only State Certified Hospice Demonstration Program opened at United Hospital to begin caring for cancer patients who had a life expectancy of six months.

United Hospital offers the Hospice program of care to patients and families primarily in their homes, and when care at home can no longer be successfully provided, hospital care is available. To date we have cared for over 100 patients and families, and are currently carrying an active bereavement caseload of 47 patients. Referrals to the program are double last year's rate reflecting increasing public and physician support of Hospice Care as an effective substitute, both medically and emotionally, for more aggressive expensive acute therapies. United Hospital, in fact, has not only enjoyed local and statewide recognition of its competence, but most recently, nationwide attention as evidenced in February's issue of McCall's Magazine.

Yet, despite this increasing public and physician support of Hospice Care, the nation's health care reimbursement system does not recognize Hospice as an alternative health care service. Providers of health care continue to be penalized if they make Hospice care available instead of keeping terminally ill patients in the more costly mix of traditional curative services. In addition, terminally ill patients are likewise penalized through a loss of health benefits if they choose the Hospice alternative. Our reimbursement system is such that patients and families are forced to choose more expensive, curative therapies, even when such services are not medically appropriate or desired.

The current Proposal to provide coverage of Hospice care under the Medicare program, H.R. 5180, now before Congress, would amend the Social Security Act to allow Medicare eligible patients to utilize their benefits to obtain services from Hospice programs of care. This bill removes currently existing disincentives and is structured to maximize cost savings to the Medicare Program. By adding the Hospice benefit to the hospital insurance coverage of Medicare eligible patients, currently estimated to comprise 70 percent of all Hospice patients at United Hospital, which, coincidentally, is in line with the National average, patients would be allowed to elect this benefit as an alternative to the traditional care of the dying.

Services provided in Hospice programs of care, and currently not reimbursed, i.e. bereavement, prescription drugs and sedatives, home visits by pastoral counsellors and homemakers, etc., would be covered under this legislation.

On behalf of the patients and staff of United Hospital, allow me to express our strong support for the passage of H.R. 5180. If the Bill is not passed, Hospice programs will continue to find financial viability increasingly difficult, and many will be forced to close or curtail services.

If I, or any member of my staff, can be of any assistance to you in this regard, please do not hesitate to contact me.

Sincerely,

KENNETH F. ADAMEC,
*President.*

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STATEMENT OF PAOLI MEMORIAL HOSPITAL HOSPICE, PAOLI, PA.

The following testimony concerning H5180 (Hospice Funding Amendment) is respectfully offered by Paoli Memorial Hospital Hospice. We feel our testimony will be valuable because our program is a duplicate of the guidelines outlined in H5180. Paoli Memorial Hospital Hospice has been in operation since June, 1978. Looking at us is like looking at H5180 in operation for four years.

We are an interdisciplinary team consisting of three registered nurses, one social worker, a minister and twenty seven trained (hands on) volunteers. We have available all the ancillary services of the hospital, including, pharmacology, x-ray, nutrition, a psychiatrist, an oncologist, plus a functional committee representing diversified specialists. We operate 24 hours a day, 7 days a week, providing home care and hospital care if needed. Patients are accepted with a terminal diagnosis (usually patients suffer their demise within 6 to 8 months.) We accept patients recommeded by Paoli Memorial Hospital physicians and living within a 20 mile radius of the hospital.

Patients on our hospice program may participate in many different insurance programs. We accept whatever coverage that is presented. Some companies have skilled

nursing coverage only, other insurance companies may offer additional benefits. Having a hospital based home care program, many of our patients have home care insurance covering at least 80 percent. Paoli Hospice has been fortunate in receiving funding from many foundations. Among those are the Willaim Penn Foundation and The Annenberg Foundation.

During the past four years, we have served over 200 patients. We have learned two things. One, terminal illness is very costly to society. It is extremely costly in terms of medical expense. It is costly also because often terminal illness is accompanied by family destruction, alcoholism, divorce and stress related illness, both physical and emotional for family members. Two, we have learned that Hospice works! Hospice reduces the cost of medicare care. Hospice reduces and sometimes eliminates, family stress and related problems.

We operate with the strong belief, born out by our experience of four years, that Hospice Care is Better Care. Let me introduce you to Anna Jane. Anna Jane was 48 years old. She had 8 children, four at home, ranging in age from 12 to 24 years. When the initial diagnosis of cancer was made, Anna Jane lived in an upper middle class home. By the time a terminal diagnosis was confirmed, Anna Jane was separated from here husband and the cost of her disease had forced the family to move into a lower income neighborhood. Anna's physician decided that Anna's chaotic family situation, as well as her disease, required Hospice intervention. Our Hospice Team met with the family and the patient to discover where Anna was in her disease process and what she wanted for herself.

Anna was vividly aware of what her struggle and impending death was doing to her family. Her 16 years old daughter was trying desperately to provide additional income by working part time, while keeping up with school work and cooking and cleaning for the family. The 24 year old was torn by career decisions and his need to help. Younger children were trying to help but suffered confusion and anxiety. Her family was in chaos and her pain and infirmity were worsening. She needed help in organizing and stabilizing her family. The Team sent in a Homemaker [1] Five volunteers were assigned, led by a volunteer manager. The volunteer manager worked with the Homemaker in structuring and organizing the family. Volunteers provided meals, transportation to Anna's physician, and a listening ear to Anna and members of her family. Nursing care and spiritual guidance were on-going and constant. Pain control was positive and the goal was keeping Anna as comfortable as possible, yet aware and communicating with her family.

Anna Jane utilized all of our services for the four months she was under our care. RN visits averaged twice a week, with some emergency calls in between. The homemaker came in for four hours a day, five days a week. The pastor and volunteers were in and out frequently, particularly at meal times to help stabilize that aspect of family life.

Hospice Care is family care. Because Anna was able to be at home and alert, she was able to make plans for her children. Anna's pain control (one of Hospice's exceptional benefits) was regulated and changed constantly, allowing her to live fully as her determination warranted. After Anna died, her children were helped by our team through bereavement counseling for the next 11 months.

Anna received all this care, exceptional pain control, being at home with her family, counseling support for ail of them, homemaker services, and intangibles, such as peace, for much less cost than just Anna's care would have been under traditional systems. To be specific, Anna's total hospice home care cost for four months was $3,836.26. Our records show that 2½ months prior to her death nursing visits increased. Her disease had progressed to such a point that without our services Anna may have been institutionalized. Assuming she would have come into our hospital for those 10 weeks, bed and board alone would have been $11,550. Ancillary charges, such as supplies and medication would have added to the bill. Had she chosen to go into a nursing home in our area, bed and board alone, without any medical care, would have been $3,920 for 10 weeks. Because Anna's children would have been alone, a welfare agency would have been called for support. If a children's service supportive agency were identified, additional costs for foster care may have been indicated.

To examine the pain control more specifically, Anna's pain became unpredictable and at times indescribably intense. At such times, often in odd hours, our team would receive a call from Anna's daughter. Our nurses have intimate knowledge of each patient and access to the physician in charge to dispense pain medication. They also have continuous cooperation from our pharmacy. These factors enabled our nurses to have effective pain control to Anna, usually within 30 minutes. What

[1] A person who fulfills the duties of the missing homemaker.

would have happened had her need manifested itself at 3 AM Sunday morning? Without a hospice team Anna would have waited a long time using outside services.

Anna is just one of 200 patients and families we have served. Her case is typical. It has been our experience that 98 percent of our patients under hospice care opt to avail themselves of home care services. The other 2 percent are patients having no family support, an inadequate home situation, or have died within a 48 hour period. For basis of comparison, one day at Paoli Memorial Hospital, bed and board only, costs $165.00 a day. Bed and board at a local nursing home costs $56.00 a day. A professional team visit by our team costs $28.00.

Hospice makes terrific sense in just medical savings alone. I'm sure you've been told that just 8 days out of the hospital and hospice pays for itself. The cost savings are easily documented from our records. The savings from future problems stemming from terminal illness are not so easily documented. Those of us who work in this field know that the savings are great. We urge you to fund H5180 as written. If you do, our program will continue and others like it will begin. Americans will receive better, more comprehensive care than is now available and at much less cost to their families and the government and insurance companies.

Paoli Memorial Hospital is located in Southeastern Pennsylvania, between Philadelphia and Lancaster. Please come and see us, talk to our team, and see for yourself how H5180 works.

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STATEMENT OF DENNIS REZENDES, BOULDER, COLO.

SHOULD THE PASSAGE OF HOSPICE REIMBURSEMENT LEGISLATION BE HELD HOSTAGE TO THE HCFA DEMONSTRATIONS?

Mr. Chairman and Members of the Congress: My name is Dennis Rezendes, and I appear as a private citizen who has devoted eight years to the development and delivery of hospice care within the United States. I am employed as Vice President of the National Alliance of Business and I reside in Boulder, Colorado.

My background for appearing before you today relates in part to the fact that I managed and directed the nation's first hospice, the Connecticut Hospice, from its early inception through the development of its home care program and inpatient facility. I am given the credit or blame for founding the National Hospice Organization and I was its first executive, an original member of its national board of directors, and represented NHO in its dealings with the private insurance sector and with the federal government.

In my capacity as the spokesperson and designated representative of the National Hospice Organization, I initiated the conversations and negotiations in 1976 with Members of Congress and the then-named Department of HEW which resulted in the Health Care Financing Administration Hospice Demonstration Project.

I served as the Chief Executive Officer of the Connecticut Hospice during the design, start-up, and implementation phases of the HCFA demonstration project and chaired the steering committee which represented the 26 demonstration sites in their negotiations with HCFA.

The question has arisen. "Why not wait for the HCFA Demonstration to be completed before taking any congressional action on hospice reimbursement? Why not put H.R. 5180 on the shelf until the evaluation of the HCFA project is finished?"

Based on my experience in the hospice movement, nationally, and my intimate knowledge of the HCFA Project, I must strongly disagree with the notion that the Congress should hold hospice hostage to this single demonstration effort.

As, perhaps, the primary person within the hospice movement involved in the decision to create the HCFA demonstration project, I must testify that neither the design nor the results of the project implicate, in substance, the pending legislation before the Congress.

After substantial preliminary negotiation in 1976 with Congressional personnel and within the Department, the decision was made, informed by the strong views of staff of the Senate Finance Committee, to seek a demonstration of hospice care reimbursement alternatives through HCFA under the authority given HCFA in Section 402 of the 1967 Social Security Amendments.

The goal was to provide basic cost data, definitions, and alternative methodologies tha would serve to inform a national reimbursement policy.

In 1977, commitments were made within the Department to proceed to design such a demonstration effort. We were assured by responsible persons in high authority in the Department that a project could be underway "in a matter of a few months."

However, a year and ten months went by, consumed by continuous work with HEW and HCFA and the beginning of what would be a record of delays, missed deadlines, and befuddled schedules plaguing this project.

Finally, on October 4, 1978, the Secretary of HEW, Joseph Califano, announced the Hospice Demonstration Project publically before the National Hospice Organization convention. The commitment was made to proceed. Scheduling promises were made that led the hospice movement to conclude that "in a matter of a few months" the project would be underway.

Yet, contrary to assurances, it was a full twelve months more before the Department finally announced that there would be 26 demonstration sites. By then, October 1979, had arrived.

Then, what was to have been a 90-day start-up phase turned into yet another year of deliberations, waiting, false starts, and missed deadlines.

It was not until October 1980, that the Demonstration actually, finally got underway.

The choice of an independent evaluator, a lynch pin in the meaningfulness of the entire effort, was not finalized, either, until October, 1980, well after promised deadlines.

The unfortunate fact is that, leaving aside the two years of design time from 1976–1978, a further two years of delays were consumed after the Secretary, himself, publically announced the start of the project before the project actually began. And, on the date of beginning, October 1, 1980, no definite evaluation plan or model had been developed or agreed upon to monitor or evaluate the sites.

Associated with these major delays were repeatedly-missed, month-to-month deadlines and postponements from March 1980 (a "final" start-up date solemnly promised by HCFA) until October 1980, the actual date of start-up. These month-to-month postponements created substantial additional costs and program chaos for the 26 sites. Thousands and thousands of dollars in such costs were passed on to the sites and pushed forward into the beginning of the demonstration period, itself. One site reported $7,500 in accounting costs, alone, related to accommodating HCFA's indecisions between March and October, 1980.

Frankly, it was in large part through congressional pressure and the serious personal concern of Members of Congress that the project was finally underway in late 1980. Members of Congress who had been persuaded by HCFA assurances and who had then passed those assurances on to constituents suffered embarassment.

So much unnecessary cost and so many unexplained delays were incurred that HCFA and it independent evaluator ultimately decided, in 1981, to simply discount and ignore the first half and perhaps the first full year of cost data as being unusable for the demonstration's goals.

The impact of this admission is that only the last one half of the demonstration project period can be looked at for any reliable data, at all, particularly insofar as cost is concerned. The likelihood is that only the third quarter 6-month period (months 13-18) will be considered in an effort to have data sooner than called for in the timetable of the project.

In any case the fact is that HCFA will not have audited cost figures on the first year ending September 30, 1981, until July of 1982, and that final audited cost figures on the second twelve month period ending September 30, 1982, will not even be generated by the sites, themselves and then authenticated for even audit accuracy purposes before July, 1983.

In connection with the decisions to discount much of the first half of the demonstration cost data, it is interesting to note than on-site evaluation staff were not even in place until July, 1981 (the project was nearly half over by them), and did not begin to actually evaluate the programs before August, 1981.

The first eleven months of the HCFA Hospice Demonstration Project passed with no on-site evaluation taking place.

In fact, beginning in 1977 the HCFA Hospice Demonstration Project has been victimized by a series of missed deadlines and re-designs that continued well into late 1981. In fact, the evaluation by the independent evaluator is not targeted to even be given to HCFA until the end of 1983.

How far into 1984 will it be before HCFA gets around to analyzing the evaluation and begins to formulate internal policy options and internal recommendations? How much more time will then elapse as the Department, itself, having discovered the extent to which the data needs to be discounted, focuses on a position? How much more time will it take for the Administration, even given a generally supportive attitude toward hospice, to make legislative proposals to the Congress?

Given the record, I cannot give the Congress much reason to take comfort in HCFA's assurances on this matter.

Aside from the central question of timeliness posed by what will end up as an eight-year process from start to finish, there are other serious questions about the value of the data as it relates to a national reimbursement policy, or, specifically, as it relates or doesn't relate to H.R. 5180.

One of the primary reasons why Congressional direction led to a HCFA hospice study was to test hospice vis a vis reimbursement methodologies. Yet, it must be noted for the Record that the study is not testing or studying reimbursement techniques whatsoever.

The first of many sacrifices to the integrity of the evaluation process was the decision by HCFA to not study reimbursement alternatives, despite the original study design and announcement.

The typical, cost-based retrospective Medicare reimbursement system is being used even though most of the 26 sites proposed alternative systems.

When this demonstration is over, the Administration and the Congress will know no more than they know today about the effect of varying approaches to reimbursement on the delivery and costs of hospice care.

Furthermore, no effort is being made to study or evaluate the substitution effect of hospice as an alternative in any scientifically useful way.

A general consenses has developed among those who lead the hospice movement and those who have already studied it extensively, that hospice is most PREDICTABLY cost effective and achieves the most IDENTIFIABLE savings when it is provided as an alternative to the traditional modes of dealing with terminal illness. This substitution approach is the heart and soul of H.R. 5180 and is the basis for its passage by a cost-concerned Congress.

Under H.R. 5180 the hospice benefit is not hoped to be a substitute for acute care. It is not wishful thinking or a projection. H.R. 5180 mandates that the hospice benefit be elected, chosen by the patient instead of other forms of Medicare-covered care. Aside from affirming the hospice principle that persons receiving hospice care have made a conscious decision to forego curative therapy, H.R. 5180 takes the mystery out of whether hospice is an alternative or an add-on.

H.R. 5180 does not leave up to the market, to chance, or to esoteric social science predictions whether hospice will, in fact, be a substitute for the more-expensive, less-appropriate system in place presently. The HCFA demonstration does not address the impact of such a mandated, clear policy of substitution.

Thus, the HCFA Demonstration Project does not implicate or even relate to what is the reimbursement essence of the legislation before you.

In fact, a major flaw in the HCFA Demonstration is its lack of any testing of a consistent, standard definition of hospice care such as that which is set out in H.R. 5180.

This means that the major cost data of the demonstration will be to documentation of the negative effect of the current jumble of reimbursement systems and policies on a hospice program of care. The demonstration project will document the problem but not implicate the proposed solution which is before you in the form of H.R. 5180.

The demonstration will document the impact of fitting the "round peg into the square hole" nature of present reimbursement coverage of hospice services, without a direct testing of a comprehensive hospice reimbursement policy and mechanism.

The waiver approach to the study of hospice reimbursement is helpful, but it must be remembered that the HCFA Demonstration approach to hospice reimbursement is, at the very best, to "shave off some more of the square corners of the square peg to better accomodate the round hole." The demonstration project does not demonstrate and will not inform the Congress in any way about the costs or service implications of a round peg in a round hole, which is what H.R. 5180 would accomplish.

Although utilization levels within a hospice for types of service are being looked at in the demonstration, no scientifically meaningful research is being conducted to help define the market for hospice care in America. Questions the Administration has about induced utilization won't be answered and aren't even being asked by the demonstration project.

The HCFA demonstration will shed no further light on what is already known about who will choose the hospice alternative.

The market-limiting factor of mandated substitution in H.R. 5180 will not be addressed by HCFA's data or data-gathering approaches.

The separate provider agreement requirement of H.R. 5180 and its substitution effect will foster competition in the markpetplace for terminal care. The outcome of this will be a force to shift terminally ill patients to the less-costly, more-appropriate hospice setting.

The most valuable contributiion of the HCFA Demonstration Project is the good work accomplished in developing service definitions and procedures, which will save the Department time in implementing H.R. 5180. The provider manual, in large part, already exists thanks to the demonstration effort.

The additional data being gathered regarding procedures and management of a hospice program will perhaps be available and perhaps of great value to HCFA, itself, in the ongoing implementation of H.R. 5180. The point is that the affirmative work products of the demonstration are already incorporated in H.R. 5180. The ongoing tweaking of hospice reimbursement will likely be aided byother information coming from the demonstrations, as well.

Moving H.R. 5180 through the Congress now will help HCFA make its most cost-effective use of the demonstration data as it comes available if it comes available.

When considered in terms of the historical context of available data on hospice care in America, one can further understand the lack of necessiry for holding H.R. 5180 hostage to the HCFA demonstration conclusions.

In 1976, when the process of the HCFA demos began in the Congress and in the Department, there was an admitted paucity of meaningful data about hospice care. Now, however, in the ensuing five to six years, an avalanche of studies, experiments, documents, and cost analyses have been compiled in the public and private sectors which have answered much of the need for research. Just a limited accounting of such non-available information would include: Four National Cancer Institute studies; the State of California Medicaid Study; the Martinson Study of Dying Children; the Kaiser-Permanents HMO Hospice Cost Studies; the Methodist Hospital/ Florida Five-year Study; the Connecticut Blue Cross Study; the Genesse Region Study; the Arizona College of Business Study; the Bloom, Bernard, Kissick Study; the Blue Cross and Blue Shield National Association Survey; the Fletcher Cost of Terminal Care Study; the NHO Delivery and Payment of Hospice Services Study; the NHO Ad Hoc President's Commission Report on Hospice Reimbursement; and the Van Buren Hospice Home Care Cost Analysis

Additionally, the National Hospice Organization has now adopted its Standards and Principles of Hospice Care document which fully defines the hospice benefit. There is no mystery about what hospice is or what it ought to be within the mainstream of the hospice movement in America.

Likewise, numerous states have adopted hospice licensing laws. Many state legislative committees have studied the hospice definitions and have codified them. The NHO Standards are recognized legally, medically and in major national commercial insurance plans. To urge waffling about a hospice benefit because of an uncertainty about what hospice is avoids the obvious.

The impact of every study and every experiment is an inescapable conclusion that when substituted for the array of other Medicare-covered care, hospice is not a cost item but is either a "wash" or a savings item. Likewise, the universal impact is that hospice is found to be a more appropriate form of care for those terminally ill persons who choose it.

At best, the HCFA study will confirm what is already known. that will be helpful, but not significant enough to postpone action on H.R. 5180.

This is particularly true in light of the lack of meaningful study being given by HCFA to the impact of choosing hospice instead of other forms of care.

If the demonstration's goal is to define the hospice benefit in terms of its component services with an eye toward decisions about which "pieces" of the benefit Medicare may cover, then that is a matter easily addressed in regulatory language and will not be hindered by passage of H.R. 5180. In fact, early passage of H.R. 5180 will have the desired effect of allowing HCFA to be "out front" of the development of the hospice movement in a creative and positive way because the separate provider status provisions in H.R. 5180 will enable HCFA to obtain central control over hospice care costs which are, in many cases, now buried or spread across several cost reports of the myriad of agencies who may now have "pieces" of the hospice benefit brokered to them out of deference not to the needs of the dying but the peculiaries of the reimbursement system.

Rather than hiding behind the social scientists' understandable need to "complete one more study" before making a decision which will be uninformed and too late to be effective, HCFA should be calling for the passage of H.R. 5180 in order to put itself in the position of managing the emergence of hospice instead of having to catch up with hospice later.

Why isn't HCFA working with the Congressional sponsors of H.R. 5180 to refine its significant achievement by further insuring that the implementation of this bill will achieve its original intent?

The ultimate folly associated with waiting for the bureaucracy is, as usual, best illustrated by private citizens and by America's business community. Just fifteen months after being first introduced to the concept of hospice, the Equitable Life Assurance Society announced, in March, 1980, that it was adding the hospice benefit to its major medical group coverage and that Equitable was going to aggressively market the hospice benefit nationwide. Soon thereafter, the Prudential, the Connecticut General, and the Travelers all added the hospice benefit.

The proliferation of the hospice benefit within the commercial health insurance sector has universally occured without an increase in premium charges. Unlike the Medicare Trust Fund, private insurance companies have a record of actuarial projections that turn a profit. At least that is the case with the insurance companies who have added the hospice benefit. There is more than a little irony at work if the Reagan Administration wouldn't be watchful for the moral to the story.

The fact is that the private sector, evidenced by the strong testimony of the Washington Business Group on Health and Warner-Lambert before this Committee, has made the business judgment which they now commend to the Congress: when hospice is substituted for acute care, it costs less; when hospice is defined in the way it is defined in H.R. 5180, it is effective.

The private individuals who have begun hospices as volunteers or elected it as patients have spoken overwhelmingly in the past decade for the appropriateness and effectiveness of the hospice alternative.

The question is not "whether hospice" but "how hospice."

HCFA began its demonstration approach asking if hospice would be more appropriate and more cost-efective as a terminal care option. Most of the answers won't and can't come from the HCFA study for the reasons given in this testimony. Yet, most of the answers are available from other sources for those who will look.

H.R. 5180 sets a policy for hospice care reimbursement with separate provider status, mandated substitution, and comprehensive services that will result in more appropriate, certainly no more costly, and ultimately more humane care for the terminally ill.

As to whether the HCFA evaluation should be the single obstacle to the development of a sound, reasonable reimbursement policy for hospice in this country, I think not.

Let Congress legislate. Let HCFA regulate.

Thank you, Mr. Chairman.

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COUNTY OF SCHENECTADY,
BOARD OF REPRESENTATIVES,
*Schenectady, N.Y., March 18, 1982.*

Representative ANDREW JACOBS, Jr.,
*Chairman, Ways and Means Subcommittee on Health,*
*Longworth House Office Building, Washington, D.C.*

DEAR REPRESENTATIVE JACOBS: Enclosed is a copy of a resolution in favor of Medicare coverage for Hospice care passed by the Schenectady County Board of Representatives.

Our Hospice program has been most caring and cost effective. Giving support to individuals and families at the time of death and dying will manifest the nation's support for each persons dignity. At the same time it will allow for more appropriate use of acute care hospital beds and a more cost effective use of tax dollars.

I hope you will be able to support Hospice.

Sincerely,

FATHER JAMES MURPHY,
CHAIRMAN, HUMAN RESOURCES COMMITTEE,
*Schenectady County Board of Representatives.*

Enclosure.

RESOLUTION 27-82

Recognizing Hospice of Schenectady and urging congressional adoption of legislation that will provide medicare coverage for hospice care

Representative Vincent offered and moved the adoption of the following resolution; seconded by Representative Buhrmaster:

Whereas, Hospice of Schenectady has recently celebrated its first anniversary of service to the citizens of the County of Schenectady; and

Whereas, this Hospice is one of the few demonstration projects permitted in the State of New York; and

Whereas, it is appropriate at this time to recognize the valuable work of Hospice and the untold hundreds of hours expended by its volunteers in aiding and comforting the terminally ill and their families; and

Whereas, it is also appropriate to take note of the fact that federal legislation is pending which will provide Medicare coverage for Hospice care and to urge adoption of same; now, therefore, be it

Resolved, that this County Board of Representatives does hereby recognize the valuable services performed by Hospice of Schenectady and does hereby commend the work of its staff and volunteers; and, be it further

Resolved, that this County Board of Representatives does hereby further endorse and support federal legislation (H.R. 5180 and S. 1958) amending Title XVIII of the Social Security Act to provide Medicare coverage for Hospice care; and, be it further

Resolved, that a certified copy of this resolution be mailed by the Clerk of this Board to Philip G. Di Sorbo, Executive Director of Hospice; to the Hon. Samuel S. Stratton, Congressman, 28th District; Hon. Donald J. Mitchell, Congressman, 31st District; Hon. Alfonse D'Amato, Senator and Hon. Daniel Moynihan, Senator.

STATE OF NEW YORK,
*County of Schenectady, SS:*
*Office, Board of Representatives*

I have compared the preceding copy with the original resolution adopted by the Board of Representatives of Schenectady County at a meeting held February 9, 1982, on file in this office, and I do hereby certify the same to be a correct transcript therefrom in the whole of the original.

Witness my hand and the seal of the Board of Representatives, at the City of Schenectady, this tenth day of February One Thousand Nine Hundred and Eighty two.

FRANK R. SIMBOLI,
*Clerk, Board of Representatives.*

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CINCINNATI, OHIO, *March 19, 1982.*

Hon. WILLIS D. GRADISON, Jr.
*U.S. House of Representatives,*
*House Office Building, Washington, D.C.*

DEAR SIR: I am secretary-treasurer of the Southwest Ohio Society of Family Physicians (S.O.S.F.P.) Our group is composed of over 400 practicing family physicians in an eight county area of Southwest Ohio. We recently had a council meeting and discussed House Bill H.R. 5180 in regard to Medicare reimbursement for Hospice Service.

As family physicians, we are very much concerned about cost-effective medical care for our patients. We feel that Hospice is a cost-effective alternative to hospitalization for terminally ill patients. As such, we support legislation which would allow Medicare reimbursement for Hospice services.

Please include this supporting letter as testimony to be included in the committee's report on H.R. 5180.

Sincerely,

ELMER F. WAHL, M.D., *Secretary-Treasurer,*
*Southwest Ohio Society of Family Physicians.*

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ST. LUKE'S HOSPITAL,
*Duluth, Minn., March 19, 1982.*

Mr. JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means,*
*1102 Longworth House Building, Washington, D.C.*

DEAR MR. SALMON AND COMMITTEE: As Administrator of St. Luke's Hospital, I am writing to request your active support of the Hospice Reimbursement Bill (HR 5180) which is scheduled for hearing in your committee on March 25, 1982.

Our hospital presently provides a comprehensive Hospice program known as Hospice Duluth. The program, under the medical directorship of Thomas Elliott, M.D., provides an alternative to traditional acute care for terminally ill patients and their families. Because the primary emphasis is on helping to keep patients at home with

the support of their family and friends, we believe this program provides a less expensive alternative to the traditional acute care hospitalization.

We believe that provision of Hospice care results in a significant savings over traditional care for patients in the last six months of life. However, the current reimbursement system serves as a disincentive to patients wishing to choose the Hospice alternative. As you may be aware, patients can obtain more complete Medicare coverage through traditional hospitalization than they are able to obtain through care in the home through the Hospice program. Thus, it costs more Medicare dollars to provide what may be less appropriate care.

The intent of the Hospice Bill, as I understand it, is to provide for more complete coverage of Hospice services for those patients eligible under Medicare Part A. An average of 75% of our Hospice patients are Medicare recipients. In addition to the usual services such as nursing and home health aide, which are already being covered through the existing home care reimbursment system, the bill would provide for coverage of bereavement to follow-up to families, counseling to families and patient by a medical social worker, pastoral or other counselors, and brief institutionalization for respite care or symptom control. Enactment of this bill would encourage use of home care resulting in less cost to Medicare.

I do wish to express one reservation about the bill. It is my understanding of the bill as written, that a hospice program would be required to provide no more than 20% of its aggregate calendar days of care in an inpatient setting. I feel that this is unnecessarily restrictive since the bill already protects the potential overuse of the Medicare fund by setting a "cap amount" for average patient cost. The 20% limit on inpatient days could interfere with the hospice philosophy of providing care "appropriate" to each individual's needs.

Once again, I encourage and request your support of the Hospice Reimbursement Bill with the exception of the 20% inpatient day limit.

Sincerely,

E. T. EVANS,
*FACHA Administrator.*

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HELENA, MONT., *March 24, 1982.*

JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means,*
*1102 Longworth House Office Building, Washington, D.C.*

DEAR MR. SALMON: I am writing in support of HR 5180/S. 1958, the proposed hospice reimbursement bill.

Although I've only recently been personally involved in our local hospice, it is clear to me that the hospice concept works. With our skilled, professional team members and marvelous volunteers, I've seen our caseload double in a few short months. These terminally ill patients, along with their families have been given comfort, peace and support in their final time.

Our bereavement program has grown as well, and our communtiy continues to ask for hospice representatives to present program information at gatherings large and small.

Two things particularly strike me as I reflect upon hospice. First, the reduction of institutionalization is significant. As the terminally ill want and can go home, they may and still receive hospice care. Expensive hospital stays are limited while offering some peace of mind.

Secondly, our hospice literally thrives upon our volunteers. Citizens of all callings unselfishly spend hours upon hours, either in direct patient/family assistance, office work, advisory committee meetings, providing information to local groups, or other needed jobs. Our hospice is clearly an example of how local volunteers can and do make needed programs work.

In addition, passing this proposed legislation allows financial viability for hospice programs unaffiliated with existing Medicare-certified health care providers. And offering this reimbursement would result in a savings to the Medicare system since the traditional mix of covered Medicare services would be unnecessary.

I strongly urge the passage of this proposed hospice reimbursement legislation.

Sincerely,

DAVID L. THOMAS.

STATEMENT OF JOHN DOYLE ELLIOTT, TOWNSEND PLAN NATIONAL LOBBY

Since 1946, the Townsend Plan Movement has unalterably stood for complete national health insurance. Medicare, while far from complete, is national health insurance. We totally favor its completion to cover totally all our people throughout their lives for all treatment of sickness and health maintenance—in and out of hospital. Therefore, we certainly hold hospice and care and services administered in the home—all in-and-out of hospital treatment and services—essential to that goal.

Therefore, we heartily approve of H.R 5180 as embodying progress in that direction.

We have insistently held all phases of Social Security, so far, financially (and therefore, in all other respects) as very feebly meeting the real needs of our people. Medicare is not the first exception—even though it is the first Right thing yet done in the same of Social Security.

Medicare does not say to one person, "Your earnings have been low, so you are not entitled to full treatment—only half an appendectomy, for example; while to another whose earnings have been higher that he's all set for a whole appendectomy! Yet, that is just what Social Security says to our people relative to providing benefits on which depends provision for the very necessities of Life, itself!

And that is the case despite the self-evident reality that we have the Social Security problem because of our misfortuned people—not because of our well-fortuned people! Our Social Security gives the greater benefits to the well-fortuned—the LESS their Need the greater their benefit! And the Greater their Need the Less their benefit!

At this point, I have a permanent question for the Ways and Means Committee and for the whole Congress. Just what can be as senseless as developing and providing health insurance while under Social Security we consign our people to living standards which Dictate Sickness!?!

That leads me to this consideration, as embodied in the enactment of Medicare under Social Security. The perfection of Medicare and the perfection of Social Security are inseparable. They are inseparable in that neigher can be nearly what it ought to be Without the Other. Nothing can be more in vain than health care for people on living standards which dictate sickness!!

That leads me to this consideration, as embodied in the enactment of Medicare under Social Security. The perfection of Medicare and the perfection of Social Security are inseparable. They are inseparable in tht neither can be nearly what it ought to be Without the Other. Nothing can be more in vain than health care for people on living standards which dictate sickness!!

I now wish to examine what health insurance and Social Security matured really ought to mean and be.

I believe it's clear to most of us: Progressive science has long and increasingly been gaining knowledge steadily enabling more of us to live out our natural spans of life—expanding steadily our knowledge of how best to prevent and cure our ills.

To maintain health—as a physical and social reality—requires for ALL of us basic, adequate supply of the necessities of life including health—for the justice liberty God commanded for us—in the Ten Commandments. ALL Justice commands that to be the bull's-eye of the honest target of public and private human life and policy!

When we let the bull's eye out of sight, we foredoom our score before loading up!

Social Security and Medicare—both matured—aiming the greatest benefits where the Need is Greatest, opposite to now, is our honest target!

To demonstrate and prove to all mankind that this can be done by Doing it is our our Country's greatest remaining gift to mankind—if we erect it, a monument never to be outdone!

I believe, Mr. Chairman, that just about everbody must by now know that the present principles for the finance of Social Security and Medicare are futile in view of what these systems ought to be. I therefore include here how the perfection of both Social Security and of total national health insurance, Medicare, should become, can positively be totally financed on a permanently balanced set of budgets along with such permanent balance for all our public budgets.

The first requirement is this: Realize that Social Security benefits and Medicare and any temporary, or permanent future programs featuring Social Justice goals are Not Government Spending—They are people spending.

All public budgets—federal, state and local—must be cleanly split between burdens and benefits. Burdens justly require progressively rated taxes honoring equality of sacrifice on the net incomes of all persons and companies—clearly known to us all. Social Security benefits (they and health-insurances being the main projects)—

justly call for flat-rate taxes, proportionately the same rate for ALL alike, on the gross incomes (gross receipts) for all persons and companies. Just what the Townsend Plan has proposed from the very start.

If gross income taxes were employed to finance the burdens, costs of defending and managing society's public overhead, it would be crushing to the poor and of little consquence to the rich—excuselessly regressive, exactly the opposite to equality-of-sacrifice.

However, since social insurance benefits are of the mightiest consequence to the poor—important indeed to those of better fortune—and, by comparison, of little signficance to the affluent—the impact of these benefits is, itself, progressive; and, therefore, justly financed by just the tax that would be most wrong for supporting burdens, namely, the gross income tax. As the Townsend Plan has always proposed.

The highest attainment of social justice coupled with just taxation are the essentials to honest balancing of budgets. I hold it self-evident that all injustice, all wrongs, dishonesty—no matter who may fancy profit therefrom (dishonest profits!)—will, in history's inevitable balance of the books, be marked as losses, injuries, destruction—Not profits—and, above all, Not glories!

What we can't afford is social Injustice—not social Justice!

We must perfect Social Security—or perpetuate the losses of recessions, even depressions. Unemployed time is lost forever, no second of lost time ever will return to be used over!

The economists have been—generally—talking about production being the control key to inflation. I have news for them, and for all. Production depends upon the real key to employment—Market. And Market—which pays for everything directly and or indirectly—is flesh and blood, heart and soul humanity financed to command their maintainence of Life, Liberty and the Pursuit of Happiness. They speak of investing! Another evasion! Who's going to invest in any production unless he has reason for expecting it to be marketed! I believe there is no such thing as an economist who does not know that as well as he knows his own first name!!!

Is science going to make it possible for constantly more people to live the natural span of life, only for them to command living standards for the last quarter, or third of life—living standards which dictate illness!!

Only the perfection of Social Security and Medicare developed into total national health insurance can finance the Market we must have constantly to prevent depressions! This is the third time around on this depression thing. Before World War I—World War II—and Now!! The whole business is twice on the record—all the reasons for this recession-depression are bad ones—the same things are happening as happened before. Different words and names for the same things.

War is the only thing which can provide the continuing, up-to-date, employment commanding Market unless it is provided by the perfection of Social Security and national, total health-insurance

Further, perfected Social Security and Medicare—that only—can create that market in the form of the kind of prosperity upon which we depend for our ability Best to Afford All Other Things—including investment, science, education and, as well, even WAR! The consumer market in full scale, which alone pays for everything!

I repectfully present the above sincere convictions.

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VESPER HOSPICE
*San Leandro, Calif., March 29, 1982.*

JOHN J. SALMON,
*Chief Counsel, Committee on Ways and Means,*
*U.S. House of Representatives, Longworth Bldg., Washington, D.C.*

DEAR SIR: Vesper Hospice Supports H.R. 5180 and SB 1958, the proposed Hospice Reimbursement Act. Hospice services should be available to persons deserving this alternative to present health care delivery.

The Warner-Lambert Foundation cost analysis projected a savings of at least $15 million during the first year after enactment.

Therefore, enacting a bill which would allow reimbursement for comprehensive hospice service, as well as reduce expenditures for Americans eligible for medicare, is a humane, economic incentive.

On a more personal note, passage of this legislation would allow us to solve some of our reimbursement difficulties. We do have some specific concerns, as well. We will, however, hold our comments until the time period between passage and enactment. Our major concern has to do with the "covered benefit" as it relates to a person's possible need for hospitalization while under hospice care. It is sometimes diffi-

cult to separate conditions related to one's terminal diagnosis. Could this mean a potential threat to his-her hospice benefit?

Again, we see this bill as a necessary first step to correct the inequities given to the terminally ill patient and their families.

Hospice care should be a covered benefit under the Medicare program.

Sincerely,

VIVIAN SCHUTTE,
*Director.*

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STATEMENT OF SARA THOMPSON, VISITING NURSE ASSOCIATION, INC., OF BURLINGTON, VT.

My name is Sara Thompson and I am employed by the Visiting Nurse Association, Inc., of Burlington, Vermont. I represent five home health agencies covering all of Northern Vermont. Together our agencies (Visiting Nurse Association, Caledonia Home Health, Franklin County Home Health Agency, Lamoille Home Health Agency, and Orleans and Northern Essex Home Health agency) formed a coalition to establish a Northern Vermont Hospice program. Calling ourselves Respond, we were selected to become one of 26 sites in the Country to participate in the Health Care Financing Administration's Medicare/Medicaid Hospice Demonstration. This program was implemented in October of 1980, so has now been in operation for seventeen months.

We feel that our Hospice programs have been extremely successful. In the first year, we collectively served 261 Vermonters at an average home care cost per person of $1,480 or $23 dollars per day. In addition to being very cost effective, the program has been well received by patients, families and the medical community. Many letters from family members support the assumption that the services are humanitarian and in many instances make the difference between a family member's willingness to care for the patient at home or to choose more costly institutional care.

Regretably, the Demonstration will end in September of 1982 and our programs are indanger of being eliminated or greatly reduced because of poor reimbursement under the regular Medicare program. In fact, our Medicare intermediary has often denied claims for services to terminal patients in the past, stating that the patients were too sick and should be in the hospital or were not sick enough and therefore did not require skilled care. Because of these totally unreasonable interpretations, we strongly support House Resolution 5180 which could ensure the survival of our programs.

We think the Hospice legislation should be supported for several other reasons. First, the Bill attempts to preserve the integrity of the concept by defining the expectations of providers who wish to provide a Hospice program.

Second, we support the Bill because it allows for a Hospice program to be integrated into the existing health system. Nursing homes, hospitals, and home health agencies can all be providers if they meet the criteria. Clearly, however, the focus is on home care.

Still another reason is that the Hospice program will save money, in part by encouraging out-of-institution care. It is estimated that in the first year, the cost savings to the Medicare program could be $15 million or more. There are many studies to support the cost effectiveness of Hospice care. Our own experience has demonstrated this to us. Our local Blue Cross and Blue Shield was sufficiently impressed with the Respond agencies' experience to offer a Hospice benefit to their subscribers on a pilot basis. After one year's experience they have broadened this benefit to all subscribers in the two-state area of New Hampshire/Vermont and have chosen home health agencies as the providers. Another reason for cost savings is that Hospice requires family involvement and the use of volunteers. I think it is important for everyone to realize that the Hospice program will provide only a fraction of the total care needed. The primary responsibility will usually continue to rest with the primary caregiver and other family members. In addition, because of the availability of the volunteers, paid professional staff time can be reduced in part. I think the use of family members and volunteers is very much in line with what the current Administration is urging.

Still another reason to support the legislation is that it will give patients a choice. Currently, the Medicare program will usually pay for terminal illness care if patients are hospitalized. However, home care services are poorly reimbursed.

Finally, with regard to cost, the legislation does contain cost caps which should ensure that Hospice care of terminal patients does not exceed institutional costs now being incurred by the Medicare program.

In summary, we urge the Committee to support House Resolution 5180 to ensure that Hospice services will ultimately be available to all Americans when needed.

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THE VISITING NURSE ASSOCIATION OF DALLAS,
*Dallas, Tex., March 25, 1982.*

Hon. ANDREW JACOBS,
*U.S. House of Representatives,*
*Ways and Means Subcommittee on Health, Washington, D.C.*

DEAR MR. JACOBS: The Visiting Nurse Association of Dallas is a voluntary, nonprofit home health agency certified to serve Medicare and Medicaid beneficiaries. The VNA has provided home hospice care for several years, and for the past two years it has participated as one of the 26 hospice demonstration programs through the Department of Health and Human Services. In 1981 the VNA served close to 500 hospice patients through the demonstration.

The VNA supports H.R. 5180, Hospice Reimbursement Legislation, as a cost effective and humane way of caring for terminally ill patients. We urge early passage of this bill during this session of Congress in order to be able to continue our hospice program. Should the bill not be passed during this session of Congress, the VNA of Dallas and other hospices participating in the demonstration would have to discontinue a vast portion of our hospice care when the demonstration is concluded. Patients will not be admitted to the demonstration is concluded. Patients will not be admitted to the demonstration program after September 1982, and services would cease in March 1983. If that were to happen, extra expense and time (estimated at two years) would be required to build the hospice program again after the Hospice Reimbursement Legislation is passed. We have been assured that if H.R. 5180 is passed during this session of Congress, our hospice demonstration program can continue until such time as the legislation is ready to be implemented.

In view of the widespread support for the hospice bill, were urge early passage by Congress. We appreciate your attention to these remarks and request that they be inserted into the record of the hearing on H.R. 5180 before the Health Subcommittee. Thank you very much.

Sincerely yours,

ELSIE I. GRIFFITH,
*Chief Executive Officer.*

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MARCH 15, 1982.

HON. ANDREW JACOBS,
*Chairman of Health Subcommittee, House Ways and Means Committee, House of Representatives, House Office Building, Washington, D.C.*

DEAR MR. JACOBS: Having had a personal experience with the terminal illness of my only son who died at age twenty four, five years ago before Hospice of Cincinnati, I have been a home care volunteer ever since. The difference between the loving, concerned care of the hospice team working with the family and patient in their home and the lonely, isolated feeling of a hospital are beyond compare. My follow-up of bereavement of the family leads me to believe that they make a better adjustment to life without their loved one than those who have not had the help of hospice.

Please include my supportive letter as testimony to be included in the committee report on H.R. 5180.

Sincerely yours,

MRS. LOIS BOZZUTO,
*Volunteers for Hospice of Greater Cincinnati, Inc. Board of Directors.*

VOLUNTEERS FOR HOSPICE OF GREATER CINCINNATI, INC.
*Cincinnati, Ohio, March 21, 1982.*

Mr. ANDREW JACOBS,
*Chairman of the Health Subcommittee,*
*House Ways & Means Committee, Washington, D.C.*

DEAR MR. JACOBS: Have you ever gone through the trama of having a member of your family or one of your friends die from a lingering terminal illness? If you can say no you are a very lucky person.

I have been a Hospice Volunteer for 3 years and I know the hopelessness and despair these people face. Due to this experience I am concerned about bill HR 5180 now before the Congress.

Hospice believes in the dignity of the human individual allowing the dying person to be involved in the decisions of his care and treatment. This philosphy of care of the dying patient underscores a quality of living. Hospice serves persons, not their diseases. Most dying persons need communication with those around them more so than do other persons. Dying is a lonely experience. Closeness, warmth, and control of discomfort are the best palliatives. What goes on during the last few weeks or days of life are among the most important things that happen to anyone.

The unique team approach of Hospice is a comprehensive one, offering more phases of help than can be offered by the medical profession alone. Hospice includes services that help the patient and family as a unit, so that life has meaning until it is no more. It is hoped that the patient may have lived to the end and that the survivors may have grown richer by sharing in death, as in life, with the loved one.

For all the reasons above and many more it is imperative that the Hospice Philosophy, Inpatient Facilities, and Home Care Programs be kept alive and thriving independently and self governed.

Please include my supportive letter as testimony to be included in the committee report on HR 5180.

Sincerely Yours,

BARBARA C. HEIKEN,
*President.*

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VOLUNTEERS FOR HOSPICE OF GREATER CINCINNATI, INC.,
*Cincinnati, Ohio, March 16, 1982.*

HON. WILLIS D. GRADISON, Jr.,
*House of Representatives,*
*House Office Building, Washington, D.C.*

DEAR MR. GRADISON: As an active member of the Volunteers for Hospice of Greater Cincinnati, I must urge you to support H.R. 5180 to provide Hospice care under the Medicare program. Through my work as a volunteer, I have witnessed the positive results of Hospice care of the terminally ill. Hospice of Cincinnati is enthusiastically supported by a hard working and sincerely devoted volunteer membership. A vote in favor of H.R. 5180 is absolutely necessary to sustaining Hospice and the true benefits made available to those choosing it as a form of care. Please support H.R. 5180.

Please include my supportive letter as testimony to be included in the commission report on H.R. 5180.

Sincerely,

EDNA KURTZ,
*Recording Secretary.*

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STATEMENT OF WISSAHICKON HOSPICE, PHILADELPHIA, PA.

Hospice home care in the U.S.A. is relatively new. Terminal care at home is not. Despite recent trends to place dying patients in institutions many families, physicians and nurses have accommodated those who preferred to die at home. These individual acts of caring and concern have had neither the support of the skills of organized hospice service trained to assist and to prevent pain, nor any assurance that agencies such as Medicare would help to pay for home care. Medicare, on the contrary, has encouraged the institutionalization of patients. It seems regrettable that a health insurance plan for the elderly, the population segment approaching life's end, should restrict a person's freedom of choice as to where he should end his days and to underwrite and justify the high cost of confinement in a hospital or nursing home.

The concern of our organization is with patients who have suffered incurability, usually from cancer, for varying lengths of time and who have been subjected to a series of painful diagnostic, medical and surgical procedures to prolong their lives. They are, on the whole, weary of the dehumanizing features of aggressive medicine and wish to live the remainder of their lives in the comfort and privacy of their own homes. To them a hospital, dedicated to acute, life-sustaining care, is an inappropriate place to die.

In addition to comfort, hospice care offers a community research, teaching and epidemiological benefits by:

1. Reducing to a minimum the stress that is naturally a part of death.
2. Eliminating much of the psychic and social anguish of survivors.
3. Assistance to families in coping with the conflicts and bewilderment of deprivation.
4. Its records will, in time, provide opportunities for the early detection of disease in survivors.
5. Identifies psychological bereavement when it takes place.

We respectfully suggest that modifications of the proposed Medicare plan are more generous than need be and inconsistent with the acknowledged goals of hospice care to reduct cost. We suggest that four 90-day intervals is excessive and may invite abuse. One 90-day period, with one option of appeal, would appear to be more feasible. We favor any provisions that limit care to a reasonably short time and would support a realistically low cap for hospice care that would nourish the dedicate volunteer features of the movement.

We recommend a clarification of options for in-patient care—the present "short term" being open to broad interpretation. Excessive in-patient service could easily consume funds allocated for the entire hospice program, leaving home care with unnecessary financial limitations.

Summary: Home hospice care offers effective and economical relief of pain, loneliness and fear associated with dying in our culture and, to multitudes of patients desiring it, a preferable option to institutional terminal care. Its trained practitioners and volunteers are in a position to offer help to patients, their families and the community at relatively low cost. We favor rather stringent restrictions of benefits both in intervals of allowable home care and in respite hospitalization. Both in terms of economy and patient acceptability home care of the dying deserves a place in the Medicare program.

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